

# London Assembly Health Committee

## End of Life Care Investigation

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# END OF LIFE CARE



# LONDONADASS RESPONSE TO THE LONDON ASSEMBLY HEALTH COMMITTEE INVESTIGATION

## 1. Introduction

The London Branch of ADASS welcomes the opportunity to respond to the investigation into End of Life Care (EoLC). We particularly welcome the focus on:

- Understanding the challenges people face in accessing good quality EoLC and securing the care options of their choice.
- Examining how existing options can be improved for Londoners with a particular focus on the concerns and experience of older Londoners who live alone.

This submission focuses mainly on the work that LondonADASS has undertaken in this area and needs to be read in conjunction with the EoLC Alliance submission where a comprehensive response to the six questions is articulated.

Before progressing onto our submission, we would like to take the opportunity to provide a link to hear first-hand the experiences of Sanjay Chadha who wants to tell you what you can do in a proactive way, to help him plan ahead (potentially is in his last year of life)

<https://www.youtube.com/watch?v=t2bd3FghAdk>

Key areas covered by Sanjay include:

- [Living with a Long Term Condition and Facing End of Life](#)
- [Challenges and Battles](#)
- [Systems and Professional Practice](#)
- [What Can You Change](#)

## 2. Background

As the health committee is aware, on some of the key data indicators such as ‘death in place of choice’ London performs poorly in comparison to elsewhere in the country. In response to that the London Branch of ADASS originally agreed to develop and implement a programme which seeks to improve the end of life experience of individuals and their families through an effective social care contribution, with a particular focus on commissioning in Care Home and domiciliary settings.

Key achievements include

- A proactive Pan London EoLC Network established with membership across wide range of statutory and voluntary agencies
- Benchmark local progress in implementing the [End of Life Care Charter](#) that all London Directors of Adult Social Services have signed up to
- Identification of funded training opportunities that can help build the capacity and skills of the social care workforce in London in relation to EoLC
- Production of a powerful training tool featuring an interview by a social worker with an individual who considers himself to be in his last year of life
- Identification and dissemination of the “key ingredients” that should feature in contracts to support improvements in EoLC

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- Developed a consolidated hub hosted by [LondonADASS](#) for sharing good and innovative practice

### **3. How the Mayor can help**

We feel a focus on the following would improve the EoLC experience of London's residents

- Challenge Health and Wellbeing Boards to focus on EoLC of including a learning & development strategy
- Call for training in EoLC of all social and health care staff in all settings
- Call for equitable access in all boroughs to appropriate levels of community nursing and Specialist Palliative Care
- Highlight need to shift resources from acute to community providers to manage care out of hospital
- Ensure provision of adequate housing for the increasing numbers of elderly in the next 15 years to facilitate them remaining in the community
- Adopt city-wide tactics proposed within the Compassionate City Charter

### **4. Key highlights over the last year**

#### ***Commissioning person centred care for the last year of life***

We ran an event in September 2015 focused on:

- The benefits and challenges facing social care in this area
- The benefits and challenges with accessing Continuing Healthcare services
- The challenges of commissioning an equitable services across client groups and specific non cancer related conditions

121 people attended the event mainly from a commissioning background. Aspects which participants felt were most useful included:

- Everything, mainly the film and patient involvement. We need more Sanjay's to speak up
- Focus on the views and experiences of Sanjay through the video presentation and the fact that he stayed throughout the day to speak to commissioners and hear the debate
- The presentation by Sanjay set the 'person centred tone and made people think at the workshops about the impact of their decisions. There was reference back to the video throughout the day
- Possibilities of networking and sharing knowledge and experiences
- Personal experience showed by film - 'expert by experience'
- Understanding how Fast Track Continuing Healthcare (CHC) works and different ways of assessing it
- Discussing the EoLC checklist
- Networking and listening to other initiatives and examples of good practice
- Issues facing Clinical Commissioning Group commissioners

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Feedback from the event is being used to develop the programme moving forward

### ***EoLC Network***

The Network has continued to grow with now over 120 members, the main representation being from local government but also includes people from the NHS, voluntary and hospice sector as well as those who have experienced end of life care services from the perspective of loved ones having gone through it.

The network meets quarterly and has recently focused on the following topics:

- Minimising inappropriate referral to A+E
- Contributing to the development of a commissioners checklist
- Integrated urgent care
- Overseeing implementation of the Charter

### ***End of Life Care Charter***

A major success has been the development of an End of Life Charter that all London DASSs signed up to includes 21 areas and the Network is committed to monitoring its implementation. The following summarises progress made from an analysis of the most recent implementation update from local authorities:

- We have been increasingly ensuring our approach is person centred and holistic which takes a lifelong view of peoples' wishes and desired outcomes
- We have commissioned a rolling programme for social work staff to raise skills in having difficult conversations and develop their role in EoLC. Also a management programme which enables managers to meet, learn, support and discuss to ensure the role of social care is integrated in EoLC.
- We have two senior practitioners trained in adult's social care to coach and support the rest of staff when working with this client group.
- Practitioners are well aware of their roles and responsibilities.
- Personalisation is embedded in the assessment process. This is evidenced from regular supervision and appraisal
- Embed EoLC planning and key questions in assessments – this is all part of the care assessment planning
- An EoLC training programme has been ongoing for the past year
- Service users and carers are fully involved in reviews of care
- Continuity of care currently exemplified via quadrant working between GPs, health and local authority staff

## **5. Next steps for the EoLC Network**

- Working collaboratively across London to implement Ambitions for Palliative and End of Life Care
- Develop the skills and tools available to commissioners e.g. contribute to the development of the commissioners checklist

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- Continue to work closely with health colleagues to improve the CHC Fast Track pathway

## 6. Contributors

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## **End-of-life care: Compassion in Dying's response to the London Assembly Health Committee's investigation**

### **About Compassion in Dying**

Compassion in Dying is a charity that works to ensure every person gets the end-of-life care that is right for them. We believe everyone should be aware of their legal rights and choices when making decisions about treatment, including how to plan in advance in a legally binding way.

Compassion in Dying provides individuals, carers and professionals with free, clear and up-to-date information about their rights and choices through a free, national Information Service, which receives over 250 calls, emails and letters a month. We are the leading provider of Advance Decisions to Refuse Treatment, which allow an individual to set out in advance what treatments they would not want in the event that they lose capacity (which could happen, for example, towards the end of life, as a result of dementia or stroke).

Polling<sup>1</sup> shows that 82% of people say would want to make the final decisions about what, if any, life-prolonging medical treatments they receive, or have a partner or close family member make these decisions on their behalf. However, only 6 to 8% of people over 60 have made an Advance Decision or appointed a Lasting Power of Attorney for Health and Welfare (with proportionally fewer London residents having them compared to the rest of the country). Clearly there is a lack of awareness among the public of the rights they have to plan ahead for future care and treatment, and a lack of 'action' to take up these rights. In response to this our work raises awareness and provides people with support to complete Advance Decisions, Advance Statements and Lasting Powers of Attorney for Health and Welfare.

Compassion in Dying also runs *My Life, My Decision*, an outreach service funded by the Big Lottery Silver Dreams Fund. The service is delivered in partnership with Age UK East London (covering Tower Hamlets, Newham, Hackney and the City) and Age UK Hillingdon, along with five other local Age UKs across England.

Through *My Life, My Decision* we raise awareness of end-of-life rights amongst people aged over 50, offer an opportunity to discuss treatment and care preferences, and provide support

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<sup>1</sup> YouGov (2014), Reported by Compassion in Dying: Who do you want to make decisions for you at the end of life? <http://compassionindying.org.uk/library/want-make-decisions-end-life-yougov-poll-2014/>

to complete an Advance Decision, Advance Statement or a Lasting Power of Attorney (LPA) for Health and Welfare. We also deliver accredited training to professionals, volunteers and community groups in the delivery areas. Working in four London Boroughs we have experience of working in diverse parts of the city and have been able to learn from service users and adapt our service to reach a diverse range of people effectively.

**Q1: What are the main challenges for ensuring good quality end-of-life care for older Londoners who live alone?**

For anyone who plans ahead by making an Advance Decision or LPA, it is important that their wishes are known to professionals when it matters. However this is particularly important for individuals who live alone and may not have a family member or partner to draw attention to their Advance Decision or Advance Statement in the event that they lose capacity.

Whilst London has an EPaCCS (Electronic Palliative Care Coordination System) called Coordinate My Care to ensure patient wishes are known across settings, this only covers those who might be expected to die in the next twelve months and who have been formally identified as having end-of-life needs. Research tells us that groups such as non-cancer patients and people with multiple chronic conditions are frequently under-identified as having palliative needs<sup>2</sup> and as a result are not formally recorded on palliative registers, nor are they included in EPaCCS. These people, as well as those who have recorded their wishes but are not at the end of life, would benefit from a central register for their Advance Decision. Such a register would be useful for those individuals who then became more ill or frail and could be considered at or approaching end of life as their preferences could be updated and recorded on Coordinate My Care.

Through delivering *My Life, My Decision* we know that making an LPA is problematic for someone who has few or no relatives or friends, when there may not be anyone sufficiently close who would be a suitable attorney. For these people, making an Advance Decision is a more practical option, but with such low awareness amongst the public older people are being deprived of the right to plan ahead, and critically, the peace of mind that planning ahead formally allows.

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<sup>2</sup> Courtney R, Calow A (2014) Audit of Palliative Care Patient Identification in General Practice *BMJ Supportive & Palliative Care*



For example, *My Life, My Decision* in East London supported Lydia to plan ahead. She said: *“I used to worry about how I might be cared for or what medical treatments I might receive should I lose the ability to make my wishes known to those around me. I was born an only child and I’ve seen what it’s like to lose capacity and not be control of care because I’ve seen what has happened to my mother. She’s in a care home and well looked after, but I’m not sure what might happen to me when I am older. With the help of the team at My Life, My Decision I completed an Advance Decision to Refuse Treatment (ADRT) and Lasting Power of Attorney for health and welfare. I have now managed to put plans for my future in place which has given me great peace of mind.”*

**Q2: What additional challenges are faced by other groups, such as people from BAME communities?**

**a) BAME communities**

Our work in East London and Hillingdon has brought us into contact with many people from BAME communities and those organisations who work with them. These include a Gujarati women’s group, a Gurkhas group, East London Mosque, SubCo Trust (supporting elders from the Asian subcontinent), Women’s Health and Family Services’ Somali women’s group and Hibiscus Caribbean Elderly Association. We have heard from people from BAME groups that they face several challenges in relation to end-of-life care including language barriers, cultural differences around talking about the end of life and preparing for death and – for some – low trust in health services leads to them not accessing services and not planning ahead.

People from BAME communities, particularly those for whom English is not their first language, frequently find themselves excluded from accessing services and decision-making in health and social care. A Somali woman aged over 60 living in Newham attending our focus group with the Women’s Health and Family Services group, said through a translator: *“We are already at the stage where we cannot communicate with health services. We feel neglected before we reach the end of life”*. Another Somali woman from the group gave us an example: *“Yesterday I went to the hospital. I was asked if I had an interpreter. I said no, so they sent me home”*.

These problems apply across health services, but are especially pertinent for end-of-life care given the importance of open communication in making one’s end-of-life wishes known. This is further complicated by the low awareness of planning ahead tools, not just amongst the

general public but also amongst health and social care professionals and community leaders.<sup>3</sup>

## **b) LGBT people**

Research by Stonewall suggests that getting older can be more complex for lesbian, gay and bisexual (LGB) people as they are more likely to face the prospect either alone or without as much personal support as their heterosexual counterparts: *“Lesbian, gay and bisexual people share many worries about ageing with their heterosexual peers but are consistently more anxious across a range of issues including future care needs, independence and mobility, health ....”*<sup>4</sup> The same report found that 50 per cent of single older LGB people are not confident that medical professionals would identify and consult the right person to make decisions about their care if they were unable to make their wishes known themselves. These findings suggest that planning ahead for future medical treatment could be particularly relevant to meet the concerns of some older LGB adults.

Compassion in Dying is working with Opening Doors London and Stonewall to hear from LGBT people about their experiences of and concerns about end-of-life care and to provide support with planning ahead.

## **c) Overview**

It is vital that services are person-centred, with health and social care staff adequately trained to ensure that a person’s individual values, beliefs, culture, customs and practices and their wishes for treatment are respected up to and including the end of their lives.

At Compassion in Dying we have recognised the importance of working alongside and consulting BAME, faith and LGBT groups in order to understand their experiences and needs around planning ahead and the end of life. As a result we have been able to and are continuing to develop new service models and materials to make end-of-life decision making accessible and relevant to these communities.

## **Q3: What healthcare and social support is needed to ensure that more people die in their place of choice?**

Some people will prefer not to be hospitalised at the end of life, preferring to be discharged to die at home, in a hospice or in a care home. For someone who lacks capacity it is difficult

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<sup>3</sup> House of Lords (2014) Select Committee Report on the Mental Capacity Act

<sup>4</sup> Stonewall (2011) Lesbian, Gay and Bisexual People in Later Life

to ensure that this is the case unless those wishes are formally recorded and known to healthcare professionals.

Research shows that there is a lack of a systematic approach to the recording of discussions with patients or carers about end-of-life issues, and that care professionals often carry information about patients 'in their heads' rather than relying on recorded notes to support the transfer of information between staff across organisational boundaries.<sup>5</sup> Setting out end-of-life preferences in an Advance Decision or Advance Statement or appointing an LPA for Health and Welfare is crucial to ensure that those wishes are respected, including preferences over where one is cared for towards the end of life. Making an Advance Decision refusing life-prolonging treatment can also help prevent emergency admissions to hospital in the event of a crisis in a person's last days of life<sup>6</sup>. Having these discussions early also makes it more likely that the support needed to enable someone to die at home – including practical support for their informal carers – can be put in place in time.

The Care Quality Commission is now examining end-of-life care in inspections of GP surgeries, hospitals and care homes which usefully include evidence of discussions and recording of patient preferences. This information should be valuable when policy makers and commissioners are planning health and social care support, specifically around discharge and planning.

#### **Q4: How is the quality and availability of end-of-life care affected by the diagnosis received?**

Our society is ageing and, as a result, we are seeing an increase in people who are diagnosed with multiple chronic and terminal conditions. At diagnosis it is important to ensure that individuals are made aware of their rights for when they no longer have capacity. It is crucial that patients have access to this information even if they choose not to act on it. If individuals are not made aware of their diagnosis and anticipated prognosis they won't have the information on which to base future treatment and care preferences.

Alongside this condition-specific focus, it is important to address those people who are 'well' or who are undiagnosed and not in receipt of specialist care who need to be given the

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<sup>5</sup> Cox K et al (2011) Is it recorded in the notes: Documentation of end-of-life care and preferred place to die discussions in the final weeks of life *BMC Palliative Care* 10(18) doi:10.1186/1472-684X-10-18 10; Munday D, Petrova M, Dale J (2009) Exploring preferences for place of death with terminally ill patients: qualitative study of experiences of general practitioners and community nurses in England *British Medical Journal* 339:b2391 11; Paget A, Wood C (2013) *Ways and Means Demos*/Sue Ryder

<sup>6</sup> Compassion in Dying (2015) *Plan Well, Die Well* <http://compassionindying.org.uk/library/plan-well-die-well/>

opportunity to set out preferences in advance to avoid being given care that is unsuitable or unwanted.

**Q5: How well equipped are London's health and social care providers to deal with a rising and ageing population?**

A frequent concern we hear from our service users is that health and social care providers are either unaware of, or do not sufficiently understand the use of planning tools. Evidence demonstrates that the training needs of care professionals in relation to the Mental Capacity Act and patient planning tools are not being met. Our Information Line receives hundreds of calls each month. 8% of our Information Line service users report that their GP had not heard of Advance Decisions.<sup>7</sup> A 2014 RCN survey of their members revealed 58.5% of nurses reported instances where their patients' wishes had been unable to be fulfilled over the last six months. Furthermore, 49% said that they did not always have the chance to discuss with patients how they would like to be cared for during their end-of-life period.<sup>8</sup>

We know from our work with community stakeholders that training in discussing end-of-life rights increases confidence to raise this sensitive issue amongst people who work with older adults. As with older people themselves, we found that community stakeholders wanted varying amounts of information. Some wanted an overview of end-of-life rights and the MCA and somewhere to signpost their users to, whilst others wanted in-depth training so that they could support their clients directly.

In its first year My Life, My Decision ran awareness raising talks and events in Hillingdon and East London which reached 318 professionals as well as 1,196 members of the public. A community stakeholder manager in East London who received training from Compassion in Dying's *My Life, My Decision* project commented: *"Until we had the training we couldn't gauge what people's knowledge of it (end-of-life rights) was...I had presumed that staff had more knowledge of the difference between Advance Decisions and an LPA, so I had asked for training around 'starting a conversation'. It then became evident that we actually needed more on what's the difference, the legalities and then dispelling the myths, like is an Advance Decision set in stone?"*

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<sup>7</sup> Compassion in Dying (2015) Plan Well, Die Well <http://compassionindying.org.uk/library/plan-well-die-well/>

<sup>8</sup> Royal College of Nursing (2014) <http://thisisnursing.rcn.org.uk/members/updates/why-we-need-to-talk-about-dying>

Older people in London are often reliant on community and voluntary organisations to provide outreach in non-acute settings. It is important that these organisations are given the support necessary to perform these functions to their full abilities and to best serve local communities. Without London-wide support for important end-of-life coordination initiatives, the patchwork of care and postcode lottery will continue.

**Q6: How can the Mayor support better end-of-life care for all Londoners?**

Our recent ‘Plan Well, Die Well’ report found evidence to suggest that discussing and meeting individual preferences at the end of life increases the chances of having a ‘good death’.<sup>9</sup> The research in the report found that when patients’ wishes were recorded, they were 41% more likely to be judged by loved ones to have died well. Where end-of-life wishes were not recorded people were 53% more likely to receive treatment they did not want. Crucially, the results showed that formally recording end-of-life wishes can have a positive impact on improving end-of-life experiences, preventing unwanted treatment and reducing avoidable hospital admissions.

One of our service users put it in her own words: *“Now I’ve made my Advance Decision I have greater peace of mind and I can keep myself focussed on the things in life that I enjoy.”*

Planning ahead for people’s end-of-life care should be a priority in London’s public health plans so that people are more likely to have the death that they want. The Mayor can encourage the good practice already in place in parts of the city to be further rolled out so as to address geographical and socioeconomic disparities in end-of-life care. By using volunteers and existing social networks, this work will have long-term sustainability, and by putting people at the heart of care decisions this work fits in with current policy on promoting active participation in decision making.

The Mayor can also provide support and funding to community and voluntary organisations working on the ground who are performing much of the work that is improving end-of-life care in London. By necessity much of this is on a local level, but with additional support these could become London-wide programmes and tools that would improve end-of-life care for all Londoners.

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<sup>9</sup> Compassion in Dying (2015) Plan Well, Die Well <http://compassionindying.org.uk/library/plan-well-die-well/>

## **London Assembly-Health Committee: End of Life Care - Call for Evidence**

Thank you for inviting the GMC to respond to the London Assembly Health Committee Call for Evidence on End of Life Care. This document responds to three of the questions posed and outlines the range of work that we are both leading and doing in partnership to prioritise this important area of care.

### **Our role**

We are an independent organisation that helps to protect patients and improve medical education and practice across the UK. In essence we:

- Decide which doctors are qualified to work here and oversee UK medical education and training.
- Set the standards that doctors need to follow, and make sure that they continue to meet these standards throughout their careers. We do this through the guidance that we produce on good medical practice which sets out the professional values, knowledge, skills and behaviours required of all doctors working in the UK.
- Take action to prevent a doctor from putting the safety of patients, or the public's confidence in doctors, at risk.

Every patient should receive a high standard of care. Our role is to help achieve that by working closely with doctors, their employers and patients, to make sure that the trust patients have in their doctors is fully justified.

We are independent of government and the medical profession and accountable to the UK Parliament. Our powers are given to us by Parliament through the Medical Act 1983.

### **Our guidance on end of life care**

Supporting doctors to provide high standards of end of life and palliative care has been a priority area for the GMC since 2010 when we published our guidance on [Treatment and care towards the end of life: good practice in decisionmaking](#). We published this guidance in response to feedback from doctors and the public about the issues that they find most challenging to tackle when a patient is coming towards the end of life.

Our guidance provides a fairly comprehensive framework for ethical practice reflecting the legal requirements in the UK and expected standards of good practice. It sets out how we expect doctors to work in partnership with patients and their families, the multi-disciplinary team and others across health and care services to meet the needs of individual patients. It places emphasis on effective communication with patients and their families; advance care

planning; and attention to providing a good standard of clinical care which includes the provision of palliative care when appropriate and not just in the last days of a patient's life.

The following sections of our guidance may be of particular interest to the Committee in relation to this call for evidence:

- Advance care planning (paragraphs 50-62)
- Cardiopulmonary resuscitation (CPR) (paragraphs 128-146)
- Working in teams and across service boundaries (paragraphs 17-21)
- Resource constraints (paragraphs 37-39)

To help doctors navigate and work with our guidance, we have published a range of [resources](#) that illustrate how the principles might apply to complex or challenging situations that arise in treating and caring for patients who are reaching the end of their lives.

In providing these additional resources, we are responding to research evidence which indicates that doctors, who have many demands on their time, value guidance and support that is quick and easy to access in their day to day work. The research is published on our website [here](#).

## **Q1. What healthcare and social support is needed to ensure that more people die in their place of choice?**

In our guidance on [Treatment and care towards the end of life: good practice in decisionmaking](#), we state that doctors should consistently do the following to help ensure that more people die in the place of their choice, amongst other things:

**Capacity:** In our guidance, we say that if a patient in the care of a doctor has a condition that will impair their capacity as it progresses, or is otherwise facing a situation in which loss or impairment of capacity is a foreseeable possibility, the doctor should encourage them to think about what they might want for themselves should this happen, and to discuss their wishes and concerns with the patient and healthcare team. The patient's preferred place of care and how this may affect the treatment options available should be covered in these discussions (paragraph 53).

**Cardiopulmonary resuscitation (CPR):** We also say that, if cardiac or respiratory arrest is an expected part of the dying process and CPR will not be successful, making and recording an advance decision not to attempt CPR will help to ensure that the patient's last hours or days are spent in their preferred place of care by, for example, avoiding emergency admission from a community setting to hospital (paragraph 129).

**Advance care planning:** In our guidance, we define this as the process of discussing the type of treatment and care that a patient would or would not wish to receive in the event that they lose capacity to decide or are unable to express a preference. A patient's preferred place of care is an important aspect of this. Doctors who go through this process seek to create a record of a patient's wishes and values, preferences and decisions, to ensure that care is planned and delivered in a way that meets their needs and involves and meets the needs of those close to the patient (page 85).

**Qs 2 and 3. What are the main challenges for ensuring good quality end of life care for older Londoners who live alone? What additional challenges are faced by other groups, such as people from BAME communities?**

In the public consultation that underpinned the development of our end of life care guidance, professionals and patients highlighted the challenges in accessing palliative and end of life care experienced by some groups of patients. We draw attention to this in the following paragraphs of our guidance on equalities and human rights:

- Whilst doctors must give patients who are approaching the end of their life the same quality of care as all other patients, we recognise that some groups of patients can experience inequalities in getting access to healthcare services and in the standard of care provided (paragraphs 7-8).
- It is known that some older people, people with disabilities and people from ethnic minorities have received poor standards of care towards the end of life. This can be because of physical, communication and other barriers, and mistaken beliefs or lack of knowledge among those providing services, about the patient's needs and interests (paragraph 8).

Current equalities, capacity and human rights laws reinforce a doctor's ethical duty to treat patients fairly. Our guidance makes it clear that, if doctors are involved in decisions about treatment and care towards the end of life, they must be aware of the Human Rights Act 1998 and its main provisions, as their decisions are likely to engage the basic rights and principles set out in the Act (paragraph 9).

In the references section on page 68, we also signpost to examples of external resources that may help doctors to more effectively meet the needs of disadvantaged patients and their families.

More generally, many of the challenges we were aware of when we developed our end of life care guidance remain a focus of concern today. Doctors continue to need support to understand and address:

- The ethical and legal framework for end of life care especially in the face of emerging case law
- Current expectations around good clinical practice, including the provision of specialist and generalist palliative care for a wider range of terminal conditions, and how to deliver this effectively within a complex and changing health and care system
- The potential communication barriers, including emotional and other distress that may arise, when decisions have to be made about treatment limitation and other aspects of care for a dying person.



## **Our continued prioritisation of end of life care**

### ***Helping doctors to put our guidance into practice***

Given the continuing needs of doctors in relation to end of life and palliative care, we are prioritising work to make our guidance on this more visible to doctors and patients, with a greater focus on delivering resources that can help to make our guidance as practically helpful and widely accessible as possible. To this end:

- We have recently launched a continuing professional development (CPD) electronic application ('app') for all doctors to help them plan, carry out and evaluate their CPD. We will use this to enable them to access learning and development about palliative and end of life care and promote the value of ongoing CPD to improve practice in this area. Please see further information about this [here](#).
- In England, we are working with the National Gold Standards Framework Centre in End of Life Care to deliver a partnership programme of combined guidance, training and follow on support to groups of doctors who are seeking to improve the standards of end of life care delivered to their local population of patients.
- We are working with the National Council for Palliative Care (NCPC) to produce two short films to help doctors with communication challenges such as broaching discussions about dying and questions about treatment limitation, and challenges relating to assisted nutrition and hydration. The films will also contribute to the NCPC's work through the Dying Matters Coalition.
- We are working with RCGP Wales to develop a training DVD for GPs. The content is focused on highlighting the importance of advance care planning, explaining the difference that having conversations with patients at the right time can make, signposting to some helpful sources of information and bringing a range of perspectives from doctors, patients and their families to the issue. This will be followed by a campaign to promote uptake and use of the DVD. The DVD will be sent to all GP practices in Wales and hosted on our website.
- We are developing a new dedicated section of our website that links together all our end of life care content and signposts to helpful external resources. This aims to make relevant tools and guidance more easily identifiable and accessible to doctors and other users.
- This winter, we are launching an interactive decision-making tool to guide doctors through the steps involved in supporting patients who have impaired capacity or lack capacity to make a decision about treatment and care. Many of the case studies that illustrate steps in the decision-making process will focus on palliative and end of life care issues.

Please see the below Appendix for information on our broader partnership working; regional activity; and the education and training that we provide in relation to end of life care.

## **Next steps**

We would be happy to meet with members of the Committee to discuss the issues further. And we certainly remain open to suggestions on how we might better support doctors to improve standards in this area.

We look forward to the outcome of the Committee's work.

I hope this reply is helpful. Please do let me know if you have any queries or require further information.

Yours sincerely

Mark Dexter

**Head of Policy  
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## **Appendix**

### **Broader partnership working**

Led by NHS England, the Association of Directors of Social Services and Marie Curie, the Ambitions Partnership for Palliative and End of Life Care has recently published [Ambitions for palliative and end of life care: A national framework for local action 2015-2020](#). The aim of the framework is to promote palliative and end of life care as a priority at a local level. The Partnership comprises statutory bodies including the GMC, NHS England, the Association of Adult Social Services, charities and groups representing patients and professionals.

Primarily aimed at local health and social care and community leaders, the framework comprises six ambitions:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

The framework builds on the Department of Health's 2008 Strategy for End of Life Care and responds to an increased emphasis on local decision making in the delivery of palliative and end of life care services since the introduction of the Health and Social Care Act 2012.

In addition to this, over the last two years we have been working closely with a number of stakeholders on initiatives to improve doctors' knowledge and understanding of current good practice in delivering palliative and end of life care:

- As a member of the Leadership Alliance for the Care of Dying People, we contributed to the development of the [Five priorities for the care of dying people](#) which now form the basis for end of life care provided to all dying patients in England. This is a new approach to caring for people in the last few days and hours of life, that focuses explicitly on the needs and wishes of the dying person and those closest to them, including the importance of ensuring that their palliative care needs are met.
- We are supporting NHS e-Learning for Healthcare in its work to update and promote e-learning content on palliative and end of life care.
- We contributed to the development of the Scotland 'Do not attempt cardiopulmonary resuscitation' (DNACPR) policy framework and educational materials.
- We are a partner in the newly set up NHS Education for Scotland Bereavement Hub with representation across steering, training and advisory groups. We supported set up of the [website](#) through contributing content and promoting it to doctors in Scotland.
- We actively supported the Scottish government's development and dissemination of guidance on the new Medical Certification of Death process in Scotland (which came into force on the 13 May 2015), including the circulation of a leaflet advising doctors of our support for the new guidance. As the project progresses, we will be working

with NES to develop input to training and create further links between both organisations' resources covering the broader issues relating to end of life care, particularly communication and decision support tools. As part of this, we have been developing plans to run a series of workshops for doctors across the Scottish health board areas with NHS Education for Scotland.

## **Regional activity**

We have experienced strong and continuing demand for us to deliver promotion of our guidance on palliative and end of life care.

We are frequently asked to run discussion sessions on this important issue and have developed a training package which focuses on our guidance in this area. Our teams regularly meet with and run sessions for groups of doctors; medical students and patients; clinical commissioning groups (in England); and other organisations involved in local healthcare services.

## **Education and training**

More broadly, but still of relevance, is our draft framework for [Generic professional capabilities](#). The purpose of the framework is to identify, simplify and clarify the core professional values, knowledge, skills and behaviours that we think all doctors should know about, and be able to apply and adapt to a range of clinical and non-clinical contexts, by the time they complete specialty training. It will also emphasise how doctors should be able to apply insight and awareness, to assess risk and manage complexity and uncertainty.

The framework has been developed jointly by the GMC and the Academy of Medical Royal Colleges and was the subject of a public consultation exercise between July and the end of September 2015. We are currently analysing the results of the consultation.

The development of the framework stems from a number of things. Currently, there is a high degree of variability amongst the 65 postgraduate specialty curricula for postgraduate medical training in terms of the content of professional skills and behaviours. Developments in recent years have pointed to the need for action:

- Fitness to practice (FTP) data identifies that most FTP concerns fall into one or more of the 10 core domains identified in the proposed framework.
- The high profile patient safety inquiries have consistently highlighted systems, professional and human failure.
- The review of the Liverpool Care Pathway on end of life care underlined the poor practice and neglect that can occur if essential professional behaviours and processes are not in place or care is reduced to a series of tasks.

The framework has ten domains supported by number of themes and outcomes. For example, domains include professional values and behaviours; professional skills (including practical and clinical skills); and capabilities in safeguarding vulnerable groups. The framework also focuses on areas of professionalism such as shared decision making; effective communication and team working; and humane interventions like nutrition and

hydration. These areas are common to many medical specialties, integral to all clinical care, and particularly important to palliative and end of life care.

We envisage that the Medical Royal Colleges and faculties will integrate the framework for generic professional capabilities into their curricula and contextualise it to the needs of their specialties.

To support implementation in 2017, we will consult on revised standards for curricula and assessment systems. We are also exploring opportunities to work with Marie Curie on its 'Transforming your palliative and end of life care' programme in Northern Ireland and supported a pilot training event for GPs and district nurses in March 2015.

## **Submission to the GLA Health Committee – End of Life Care in London**

**From: Greenwich & Bexley Community Hospice**

**Authors: Kate Heaps, Chief Executive; Wendy Lethem, Nurse Consultant; Dr Brendan O'Neill, Senior Consultant in Palliative Medicine; Debbie Sevant, Director of Care Services**

### **About the Hospice**

Greenwich & Bexley Community Hospice is a registered charity that provides specialist palliative and end of life care to approximately 2,500 adults with life-limiting illnesses living in the London Boroughs of Greenwich and Bexley each year. The Hospice also provides support for their carers, families and friends, free of charge.

We are the only provider of specialist palliative care in Greenwich and Bexley and for the past 21 years we have championed quality and choice in end of life care. Our catchment area covers a population of around 500,000; it is ethnically and socio-economically very diverse. We provide care at the main Hospice site in the inpatient unit, day hospice and outpatient clinics as well as providing care in the community, in people's homes, care homes, local prisons and in the Queen Elizabeth Hospital, Woolwich. We pride ourselves in giving people a real choice of where they wish to be cared for, enabling a significant proportion of those we support to die in their own homes in familiar surroundings; in 2014-15 77% of the people who were known to Hospice community services and died, did so at home/ care home (56%) or in the Hospice (21%).

The Hospice provides round-the-clock, wide-ranging services and support for people with life limiting illness and their families, carers and friends, including specialist nursing and medical care, symptom control advice and support, end of life care, rehabilitation, respite care, counselling and bereavement support, benefits and social work advice, support groups, befriending, a lymphoedema service and spiritual care. Our specialist care team includes doctors, nurses, a physiotherapist and occupational therapist, complementary therapists, counsellors, a social worker, benefits advisors and other volunteers. We also provide a significant amount of education to health and social care professionals locally and regionally.

The Hospice is a registered charity and receives around 30 - 40% of funding from the NHS, our annual turnover is around £8m which leaves over £4m to raise from the generosity of local people, organisations, businesses, community groups, trusts and foundations.

In the past 8 years, the Hospice has gone through a significant programme of organisational change, taking on the running of community services from other providers and developing these to enable the delivery of high quality and streamlined care to people regardless of where they wish to be cared for. This has been developed further with the implementation of an innovative service, the Greenwich Care Partnership, a fully integrated 24 hour community based service

which enables more people to be cared for in their home environment and has supported the Hospice and commissioners in our aim to reach more people with end of life care needs, helping to reduce inappropriate hospital admissions and reduce costs, whilst improving quality for dying people in Greenwich.

### **Why is Greenwich & Bexley Community Hospice (GBCH) submitting this evidence?**

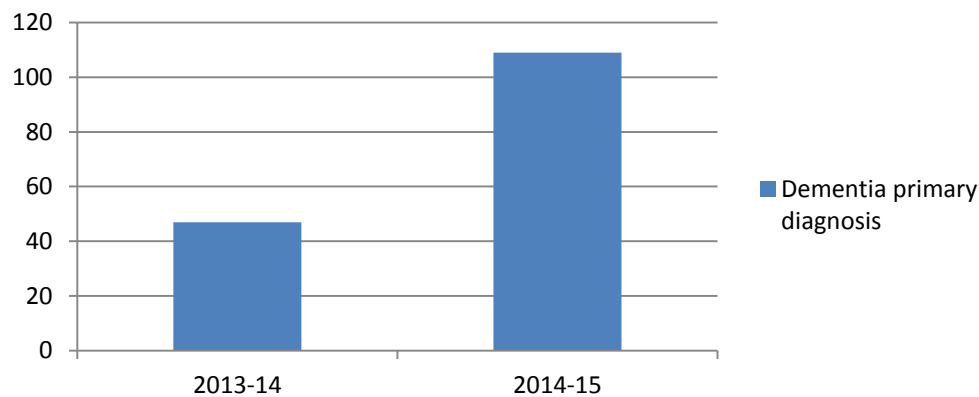
The Hospice welcomes the investigation into End of Life care in London; with recent evidence from LCA/Palle8/ Marie Curie Cancer care highlighting that 70% of London hospitals cannot provide seven-day-a-week visiting palliative care services and place of death data demonstrating that the proportion of deaths occurring in hospital is higher in London than elsewhere in England; we hope that the investigation will raise the profile of the needs of dying people in our capital and help inform strategic planning and commissioning to improve the availability and quality of care.

Over recent years GBCH has had, as one of its strategic goals, to reach more 'older old' people with end of life care needs as well as those with a non-cancer diagnosis including dementia and other 'hard to reach' groups: from BAME communities, prisoners, people with learning disability, etc.

A significant step in this plan was to introduce a Nurse Consultant into the Hospice team who has enabled us to increase our focus on the needs of the 'older old'; as a result of this we have seen a significant shift in the proportion of people who are over 85 years as well as an increase in the proportion of people with dementia as a primary diagnosis who access the care and support of the Hospice. We are building on our work with people with dementia in 2015/ 16 as a result of a grant from the St James' Place Foundation and will be working with Oxleas NHS Foundation Trust Advanced Dementia Service and Alzheimer's UK to improve and expand the services available to local people with dementia and their carers.

Age	16-24 years	25-64 years	65-74 years	75-84 years	85+ years
2012/13	0.48%	34%	24%	26%	15%
2013/14	0.28%	25%	23%	31%	21%
2014/15	0.2%	22%	21%	31%	26%

### Patients with a primary diagnosis of dementia



The Hospice has been working with local care homes with nursing for the last 8 years; developing the confidence and skills of the staff in the homes to enable them to support their residents to remain in their care home at the end of their lives; this has resulted in a significant reduction in deaths in hospital since this work began.

In addition to the focus on older people, the Hospice recently undertook to develop a strategy to improve end of life care for prisoners in our local area; there are 3 prisons in the LB Greenwich; HMP Belmarsh, HMP Thameside and YOI Isis and in 2014 we worked with custodial and healthcare staff working in the prisons to develop a strategy to enable improvements in end of life care through training of healthcare staff, awareness raising amongst remaining prison staff and better identification of prisoners who may be approaching the end of life to enable advance planning of care and realistic conversations about achievable goals in the context of their custodial sentence. This has developed our expertise to collaborate with new partners in health care provision and understand organisational differences to achieve a common aim of equitable access to palliative care. So far the strategy has had a relatively small impact when measured by population, but the successful management of one prisoner's end of life in the prison appropriately supported and accompanied by his next of kin, was a huge success in a difficult context. Although the prison population effected by this strategy is relatively small, the population as a whole is aging and it is important that this learning is shared to enable as many people as possible to have a good end of life care experience. We fear that changes to the healthcare provision and management of the prisons will reduce the impact of this work in the future.

In recognition of the importance of advance care planning and the lack of confidence and reluctance of healthcare professionals to have discussions about death and dying, the Hospice developed an innovative volunteer-led advance care planning service in 2012. This service, initially funded by Comic Relief uses volunteers who are trained to work with people facing the end of their lives to discuss preferences and wishes and to develop strategies for sharing these wishes with their family, friends and professionals involved in their care. Information about the experience of the volunteers in providing this service is available at: *Jones P,*



Heaps K, Rattigan C, Marks-Maran D: Advance care planning in a UK hospice: the experiences of trained volunteers; *European Journal of Palliative Care*, 2015; 22(3).

As outlined in the service overview (p1), the Hospice has been responsible for the delivery of an integrated end of life care service for Greenwich borough since 2011. Through this prime contractor model, the Hospice works with other providers to ensure that community provision is available around the clock to meet the needs of people who wish to remain at home. By delivering more in reach community based service, the Hospice has seen an increase in the proportion of people from BAME groups who access Hospice care; an increase from 10% to 13% across all services and 10% to 15% across community specific services in 4 years. There is more work to do to address unmet need in all groups, especially BAME communities; however we are pleased with the direction of travel. The Hospice continues to develop the model of integrated specialist and end of life care and is working with commissioners to increase access and availability of service; we hope that our evolving model will enable even greater community engagement and hope to launch an *end of life charter* in both boroughs in 2016.

As requested, we have responded to the 6 questions outlined by the Health Committee in order to help inform your investigation:

### **1. What are the main challenges for ensuring good quality end of life care for older Londoners who live alone?**

The Hospice experiences a number of challenges in ensuring good quality end of life care for older Londoners:

- a. Identification – older people are more likely to have several conditions which contribute to a gradual decline in health status, as opposed to the classic cancer trajectory. This creates uncertainty and sometimes a reluctance in health care professionals to identify the likelihood that the person might die from their condition.
- b. Expectation – (older) people with non malignant disease may not understand that they might die from their condition(s) and therefore not ask the questions that can open up a conversation about end of life care.
- c. Expectation - in our experience, older people are often more stoic about a deterioration in health and so issues with reversible causes may not be identified until later in the person's trajectory perhaps due to a crisis; this results in the end of life care episode being relatively short, beginning with an attendance at A&E/ admission to hospital and resulting in less time to plan in advance.
- d. Planning - When time is short there is little time to plan, and when the planning is done with a team who do not know the person or their circumstances, the approach to 'risk' is often more cautious; someone who has been functioning at home quite well with minimal aids and adaptations and with a low level of care is suddenly subject to a plan with a raft of equipment and multiple professionals visiting them at home, this can be confusing and not always what the person wants (or needs), alternatively an assessment may be made about the person's inability to cope in their home environment which results in

- a delay in discharge or a move to a residential care environment which may be mitigated by a relatively short package of intensive support in the home.
- e. Resource – as with other services, the Hospice is facing difficult decisions about service provision due to lack of availability and security of funding and some difficulties with staffing especially in nursing roles. We continue to look at innovative approaches to recruitment and staff development and are currently working with other Hospices in South London to develop a rotational programme for nurses who have an interest in end of life care for older people as well as to deliver an innovative Assistant Practitioner Programme to develop band 4s in partnership with Croydon College.

For those who live alone, these problems are confounded by the reduced likelihood in the person having a close family member or friend who is readily available to advocate for them if they are unable and to support them as their health declines. The choice to die at home for anyone who lives alone, regardless of age, is often less achievable than for someone with a partner or other live in carer.

## **2. What additional challenges are faced by other groups, such as people from BAME communities?**

There are a number of barriers to accessing end of life care which exist in the whole population but are sometimes more exaggerated in some BAME communities:

- a. The 'inviteability' of death/ the belief that you should not predict dying as it is God's will when you die – for some cultures/ faith communities it is seen as 'bad luck' or bad faith to talk about death and it being imminent; for this reason acceptance of end of life services e.g. Hospice care is not seen as the right thing to do. In addition, in some cultures, significant spiritual meaning can be found in the experience of the dying person and therefore the idea of certain analgesics can be challenging, especially if it has a sedating effect on the person. Hospice and palliative care services may have an association for the person with symptom control and drugs such as morphine and there may be a barrier to access as a result.
- b. Fear and denial – Many people are afraid to think about the future and plan for deterioration or accept that they are dying, or they may just not be aware; the public do not generally understand that conditions such as dementia, heart failure, COPD and MS are often terminal, too often specialist palliative care services receive a referral for a person who has been struggling with one condition for sometime, but they are not referred until they get a more 'traditional' palliative care diagnosis such as cancer. In addition some families prefer to 'protect' each other by not discussing end of life care, death and dying amongst themselves for fear of upsetting one another.
- c. Perceived/ actual lack of cultural sensitivity – can cause a barrier, as it may be uncomfortable having strangers coming into the house to provide care who may not respect traditions and culture. This may be particularly challenging where a patient requests a carer of the same gender if this is not possible. Staff may not have the necessary cultural awareness and language can also be an issue, where the patient is unable to communicate in English

and carers are reliant on informal carers rather than interpretation services to communicate. This issue can also work against patients in that the health care professional may make assumptions about the family's wish/ ability to care for their family member rather than being supported by a palliative/ end of life care service.

- d. Lack of awareness of service being free at point of delivery – many people think that one has to pay to access Hospice services, if not offered and the discussion is not had; patients and carers may not think it is an option.
- e. Hospices are seen as very 'white' and middle class, many have Christian associations, they are also seen as places only for people with cancer; this can exclude people through lack of understanding that they are there for everyone, this applies to patients, carers and some health and social care professionals. Hospices are also seen by the public and professionals as just about 'beds' and therefore the availability of specialist care in the home is not one which is always known about.

### **3. What healthcare and social support is needed to ensure that more people die in their place of choice?**

There has been a reasonable amount of research examining the evidence relating to factors which influence achievement of place of death, Cicely Saunders Institute and Marie Curie have led much of this work.

On the ground, the key factors seem to be:

- a. Has the fact that someone is likely to die been identified and have they had a discussion about their wishes?
- b. Have their wishes been shared with those who are close to them and their professional carers?
- c. Are their wishes recorded so that others can see them in an emergency?
- d. Are they under the care of a specialist palliative care service (Hospices routinely deliver home death at a much higher rate than the general population achieve)
- e. Are the necessary community services available around the clock?
- f. Do they have an informal carer who is available to support them, e.g. have the financial means and wherewithal to take time off work?
- g. Do they have an environment which will enable it? – e.g. downstairs toilet, room for a bed downstairs etc.
- h. Do they have a predictable disease trajectory? e.g. cancer

### **4. How is the quality and availability of end of life care affected by the diagnosis received?**

See above – questions 1,2,3

### **5. How well equipped are London's health and social care providers to deal with a rising and ageing population?**

All services, specialist and generalist are currently overstretched, and although we are all thinking about the need to reach more people and work differently to do so, this is challenging. Generalist staff need training to develop skills and confidence in providing end of life care and Health Education South London have a comprehensive end of life care education and training strategy which outlines the key features of this training. We all need to work smarter to reduce duplication of service and of education and to maintain and develop the workforce we have to enable them to meet the challenge. Hospices are keen to work with other partners to lead the way in this task.

### **6. How can the Mayor support better end of life care for all Londoners?**

- a. Awareness raising – getting the facts out there about palliative and end of life care, hospice care, supporting local authorities to work with their communities to understand how they can access support.
- b. Promoting volunteering in hospices, care homes, in people's homes and hospitals to combat social isolation and raise awareness positive nature of care and older people
- c. Improving transport links to community services – to promote access for outpatient services away from hospital and to help with recruitment of staff.

- d. Help with development of services and funding for Hospice and palliative care services – asking Health and wellbeing boards to investigate the level of service and statutory funding of palliative care services and promoting fundraising for Hospices with big business.

### **Further Information**

We hope that you have found this submission helpful, if you would like to hear more about the work of Greenwich & Bexley Community hospice, please look at our website [www.communityhospice.org.uk](http://www.communityhospice.org.uk) or watch our short film <http://youtu.be/RUEuM6QhfjU>. If you would like to visit the Hospice to talk to patients, carers, staff and volunteers, please do not hesitate to contact us:

Kate Heaps

Chief Executive

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Dear Lucy,

Further to the enquiry by the Greater London Assembly Health Committee, into end of life care across London, I attach a brief summary of evidence about palliative and end of life care to assist you.

This evidence is very relevant if the Major intends to improve end of life care across London; **it outlines the relative costs of care in last three months of life, and emphasises the disproportionate amount of that cost attributed to unplanned hospital admissions.**

To achieve effective care at home towards end of life, across cultural and ethnic diversity, and especially for those who live alone, we therefore need:

- **strengthening and expansion of hospital palliative care teams**, which are almost all small teams dealing with a rapidly increasing workload (see attached pan London report for evidence on this, which shows the proportion of non-cancer patients seen – greater than nationally, but rather variable. We also have data on size of these teams and volume of their work). Note that there is good evidence that early intervention from hospital palliative care consult teams improve quality of care and reduce costs (see attached May papers).
- **effective and co-ordinated care at home from social care, district nursing, and primary care, and supported by community palliative care teams.** (See attached Seow paper and accompanying editorial).

If you need any more detail about any of this evidence, please let me know.

regards,



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Publications available at: <http://www.researcherid.com/rid/C-3216-2009>

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# Economic Impact of Hospital Inpatient Palliative Care Consultation: Review of Current Evidence and Directions for Future Research

Peter May, MSc,<sup>1,2</sup> Charles Normand, PhD,<sup>1,3</sup> and R. Sean Morrison, MD<sup>2,4</sup>

## Abstract

**Background:** Maintaining the recent expansion of palliative care access in the United States is a recognized public health concern. Economic evaluation is essential to validate current provision and assess the case for new programs. Previous economic reviews in palliative care reported on programs across settings and systems; none has examined specifically the hospital consultative model, the dominant model of provision in the United States.

**Objectives:** To review systematically the economic evidence on specialist palliative care consultation teams in the hospital setting, to appraise this evidence critically, and to identify areas for future research in this field.

**Data Sources:** A meta-review (“a review of existing reviews”) was conducted of eight published systematic reviews and one relevant nonsystematic review. To identify articles published outside of the timeframe of these reviews, systematic searches were performed on the PubMed, CINAHL, and EconLit databases.

**Study Selection:** Articles were included if they compared the costs and/or cost effectiveness of a specialist hospital inpatient palliative care consultation for adult patients with those of a comparator.

**Results:** Ten studies were included and these demonstrate a clear pattern of cost-saving impact from inpatient consultation programs. Nevertheless, knowledge gaps still exist regarding the economic effects of these programs. Current evidence has been generated from the hospital perspective; health system costs, patient and caregiver costs, and health outcomes are typically not included.

**Conclusions:** Inpatient palliative care consultation programs have been shown to save hospitals money and to provide improved care to patients with serious illness. With a clear pattern of cost-saving using current methodology, it is timely to begin expanding the scope of economic evaluation in this field. Future research must address the measurement of both costs and outcomes to understand more fully the role that palliative care plays in enhancing value in health care. Relevant domains for such research are identified.

## Introduction

MAINTAINING THE RECENT EXPANSION of palliative care access in the United States is a recognized public health concern, both to address insufficient provision in underserved regions and to develop national capacity in the context of aging populations and changing patterns of disease.<sup>1–5</sup>

Evidence-based research is required, systematically appraising the outcomes of programs and identifying the key

processes and structures underpinning these outcomes.<sup>6–8</sup> Payers and policymakers require evidence to validate current palliative care provision, to explore ways that this could be made more cost effective, and to assess the case for new programs.<sup>9</sup>

One essential component of such a research agenda is economic evaluation. Patients with serious illness and functional impairment account for a rapidly increasing share of medical expenditures in the United States and other high-income countries.<sup>5</sup> Cost-effectiveness analysis of care

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provided to people with serious illness has been identified as fundamental to controlling long-term costs.<sup>10</sup>

Despite the acknowledged significance of economic analyses in evaluating and informing care provision, the economic literature on programs is small and disparate, reflecting the complexity of palliative care assessment.<sup>11</sup> Where the clinical and economic impact of palliative care programs have been analyzed in previous systematic reviews, these have tended to report across different settings, diagnoses, levels of specialism, and national systems, highlighting patterns without focusing on specific programs or models of care.<sup>12–19</sup>

There has been no economic review focused on specialist hospital inpatient consultation, the dominant model of provision in the United States hospital setting. Nonspecific approaches have been logical given the disparate and formative nature of economic evaluation in palliative care. But as the numbers of programs and of evaluations grow, so does the need for more focused analysis. A review was therefore undertaken to collect systematically the economic evidence on this model specifically, to appraise critically the evidence, and to identify areas for future research in the field.

## Methods

Identifying studies for consideration in our review was performed primarily by systematic meta-review (“a review of existing reviews”); instead of collating studies from databases, researchers considered studies included in already published reviews. For time periods not covered by already published reviews, a systematic database search was undertaken.

This was agreed among the authors as an appropriate method given the prior literature and our objectives. In the context of multiple relevant prior reviews, we did not feel that a full systematic review was justified: broadly considered, the economic evidence on palliative care programs has been assembled. What the prior reviews do not provide is a detailed examination of the economic evidence on any specific model of care delivery, or a critical assessment of that evidence. In systematically reviewing relevant previous reviews using clear criteria focusing specifically on economic evaluation of one model, we provide meaningful information that can guide decision making—the primary purpose of a systematic literature review in health care.<sup>20</sup> Formal meta-analysis combining these results using statistical modeling is precluded by persistent differences in methods and approach in economic studies of palliative care.<sup>19</sup>

Reviews were identified by systematic searches on the PubMed, CINAHL, and EconLit databases. Relevant search terms for palliative care, review, and economics (e.g., palliative, hospice; review, systematic; economic\*, cost\*) were combined to search titles, abstract, and subject headings to July 31, 2013. A review was included the meta-review only if it reported (1) a systematic search strategy, (2) examining (but not necessarily limited to) inpatient hospital palliative care programs, (3) treating adult patients, and (4) identified outcomes of interest as including (but not necessarily limited to) economic analysis. Only English-language journal articles were considered.

The meta-review returned nine published reviews with a relevant focus,<sup>12–19,21</sup> summarized in Table 1.

TABLE 1. SYSTEMATIC REVIEWS OF PALLIATIVE CARE PROGRAM EVALUATIONS

Ref #	Review	Number of included papers
(12)	Higginson et al., 2002, UK	13
(13)	Douglas et al., 2003, UK	17
(14)	Higginson et al., 2003, UK	15 <sup>a</sup>
(15)	Zimmermann et al., 2008, US	7 <sup>b</sup>
(21)	Smith and Cassel, 2009, US <sup>c</sup>	21 <sup>c</sup>
(16)	Higginson and Evans, 2010, UK	59
(17)	Simoens et al., 2010, BEL	15
(18)	El-Jawahri et al., 2011, US	22
(19)	Smith et al., 2014, <sup>d</sup> IRL	46

<sup>a</sup>Sixty-five included in total; 15 reported separately in economic analysis.

<sup>b</sup>Twenty-two included in total; 7 reported separately in economic analysis.

<sup>c</sup>Not reported as a systematic review; 21 papers discussed in cost analysis.

<sup>d</sup>Epub 2013, within the timeframe of the review.

Of these, eight systematic reviews variously focused primarily or exclusively on economic factors in palliative care provision<sup>13,17,19</sup>; reported economic impact as one outcome of interest separately alongside clinical and other factors<sup>14,15</sup>; or evaluated palliative care services without particular emphasis on economic considerations.<sup>12,16,18</sup> An additional review, not reporting a systematic search strategy but with a highly relevant focus, was included in the meta-review following discussion among the authors.<sup>21</sup> The reviews had a balance between different systems and perspectives in high-income countries with four written by teams based in the United Kingdom,<sup>12–14,16</sup> three in the United States,<sup>15,18,21</sup> and one each from Belgium<sup>17</sup> and Ireland.<sup>19</sup>

The timeframe of these nine reviews provided full coverage of the relevant published literature to the end of 2011. To supplement these findings and identify papers published since 2011, systematic searches were performed on the PubMed, CINAHL, and EconLit databases. Key search terms from the clinical and economic domains (e.g., palliative, hospice; economic\*, cost\*) were combined to search titles, abstracts and subject headings from January 1, 2012 to July 31, 2013.

## Study selection

All studies included in any of the nine relevant previous reviews and all studies returned by systematic database search were considered for inclusion in our review.

The lead author reviewed all unique titles/abstracts against the inclusion criteria; all deemed irrelevant or not meeting the criteria were removed, all others were read in full against the inclusion criteria. Where there was uncertainty about an article’s suitability for inclusion this was discussed with co-authors.

A study was included in our review only if it contained a credible economic evaluation of a specialist-led multidisciplinary palliative care consultation team to adult patients in the hospital inpatient setting, measuring and comparing the costs and/or cost effectiveness of this intervention against a usual care comparator. Only English-language journal articles were considered.

The rationale for these criteria were agreed among the authors, adapted from the gold standard guidelines for health economic evaluation.<sup>22</sup> Drummond and Jefferson's<sup>22</sup> full checklist for economic evaluations is far greater; these components were identified as constituting a fair bare minimum threshold in a field in which economic evaluation is at a very early stage. A full breakdown of the appraisal processes are illustrated in Figures 1 and 2.

### Findings

Ten economic evaluations of specialist palliative consultation teams in a hospital setting were included in our review.<sup>23-33</sup> These are summarized in Table 2.

### Summary

#### Design and approach

All 10 studies are from the United States. Observational designs dominate with 9 cohort studies<sup>23-26,28-31,33</sup> and 1 randomized controlled trial.<sup>27</sup> Among observational studies there is a wide variation in size with 5 having intervention groups of between 27 and 164 patients,<sup>23-26,28</sup> and 1 study having 4908 intervention patients.<sup>29</sup>

Nine of the studies restrict their perspective to the hospital and do not evaluate patient or caregiver outcomes,<sup>23-26,28-31,33</sup> The remaining article analyzes total health care costs for 6 months postdischarge as well as some patient outcome measures but does not quantify the relationship between the two.<sup>27</sup>

While there is variation in terms of hospital type and the label given to multidisciplinary teams, the composition of

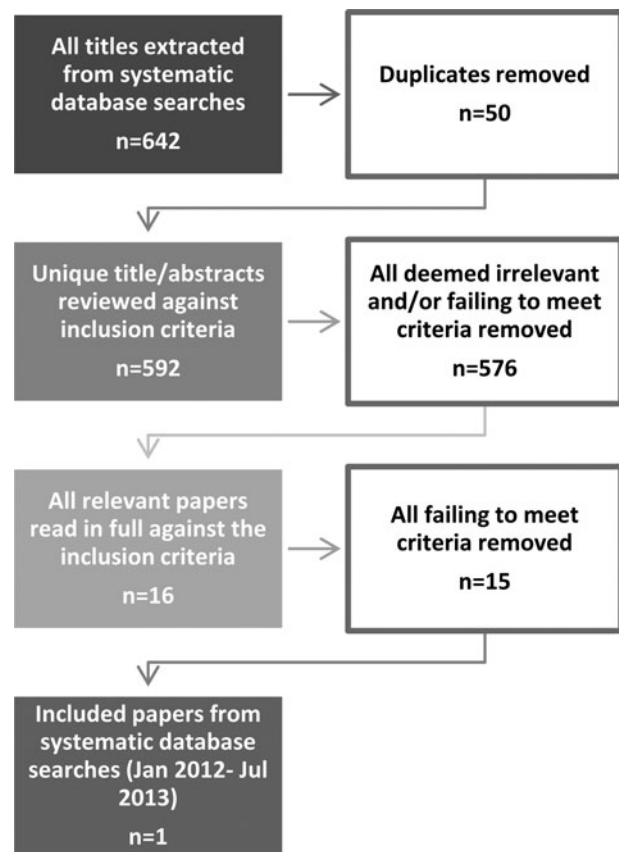


FIG. 2. Database search (January 2012 to July 2013).

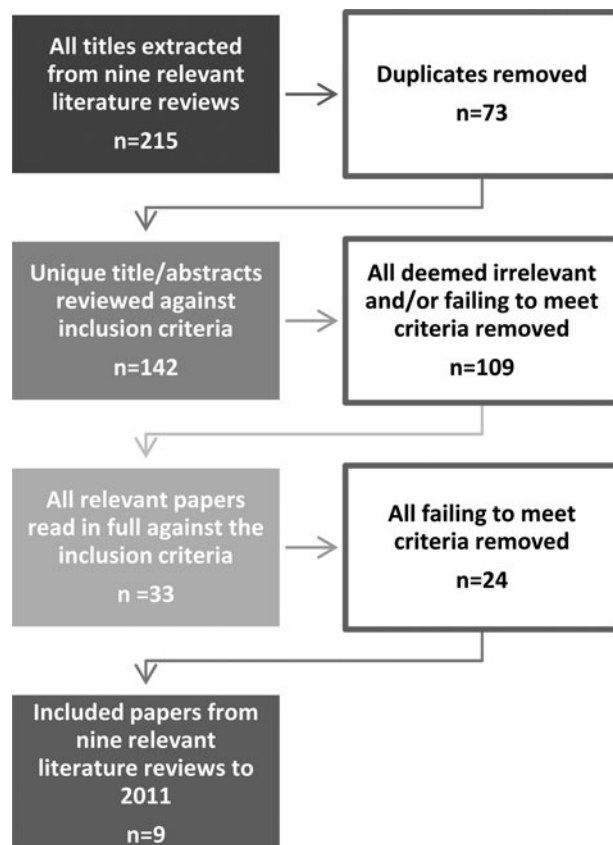


FIG. 1. Meta-review appraisal (to 2011).

those teams are broadly consistent. Six of the 10 evaluations were described as comprising at least a physician, a nurse, a social worker, and a chaplain<sup>23-28</sup>; in some cases these were also described as including a psychologist and/or an oncology nurse specialist and/or nursing assistants. Of the other 4, 2 were multisite studies in which all teams included a physician and nurse but not all included a social worker and chaplain,<sup>29,31</sup> and another assessed a newly implemented service that initially comprised a physician and nurse before later incorporating a chaplain.<sup>33</sup> The specific composition of the team was not described in one study,<sup>30</sup> but is indicated to be consistent with a prior related study.<sup>24</sup>

A further source of potential variability between studies is the process and nature of referral. All consultation teams saw patients following referral from another team in the hospital but it is not possible to ascertain how comparable these processes were.

All studies addressed programs that treated a range of diagnoses, although following matching for economic evaluation one study was restricted to patients with cancer.<sup>25</sup> Typically the study populations are patients near end of life; the survival rate during the study period for the intervention group varies between 0% and 80%, with a median of 55%.

### Results

#### Overall costs

All 10 studies report that palliative care interventions result in lower costs than their usual care comparators. There

TABLE 2. ECONOMIC EVALUATIONS OF SPECIALIST INPATIENT PALLIATIVE CARE CONSULTATION TEAMS

Ref #	Study	Hospital(s) Team label	Design	Sample size Intervention/control	Principal diagnosis <sup>a</sup>	Outcomes of interest	Key findings
(23)	Cowan, 2004	Hospital not categorized by authors ----- Advanced Illness Assistance Team (AIA)	Cohort	164 PC patients 152 UC patients	Cancer 27% Neurologic 18% Pulmonary 17% Cardiovasc. 12% Organ failure 7% Gastrointestinal 7% Chronic pain 6% Infection 4% Other 2%	Hospital charges; LOS	Lower (~7%) mean daily charges for PC than UC ( $p=0.006$ ) For patients with LOS > 7 days, PC reduces LOS
(24)	Penrod et al., 2006	Two Veterans Administration (VA) facilities ----- Palliative Care Consultation Team (PCCT)	Cohort	82 PC patients 232 UC patients	Cancer 50% Infectious disease 10% Cardiovascular 7% Pulmonary 10% Gastrointestinal 7% Genitourinary 4% Other 12% Cancer 100%	Hospital costs; ICU	PC patients 42% less likely to be admitted to ICU Lower (~22%) daily direct costs for PC than UC ( $p<0.0001$ ) Laboratory & radiology also lower; no difference for pharmacy
(25)	Ciemins et al., 2007	Large, private, not-for-profit medical center ----- Palliative Care Consultation Service (PCCS) Public hospital ----- Palliative Care consultation (PCC)	Cohort	27 PC patients 128 UC patients		Hospital costs	Lower (~13% <sup>b</sup> ) mean daily costs for PC than UC ( $p<0.01$ ) Lower (~16%) mean total costs for PC than UC ( $p<0.0001$ )
(26)	Bendaly et al., 2008	Three managed care organization hospitals ----- Interdisciplinary Palliative Care Service (IPCS)	RCT	275 PC patients 237 UC patients	Pulmonary disorders and/or MV 30% Cardiovascular disorders 23% Neoplasms 16% Infections with or without sepsis 15% Other 16% Cancer 27% CHF 9% MI 1% Other heart disease 3% COPD 13% Other pulmonary disease 1% ESRD 4% Organ failure 12% Stroke 9% Dementia 3% <sup>c</sup> Cancer 61% Cardiopulmonary diseases 11% Neurologic diseases 5% Hepatic/renal failure 4% Acute infections 14% <sup>d</sup>	Hospital charges; LOS	Lower (~16%) median total charges for PC than UC ( $p<0.001$ ) No significant difference in LOS ( $p=0.57$ )
(27)	Grade et al., 2008	Tertiary academic medical center ----- Palliative Care Consultation Service (PCCS)	Cohort	104 PC patients 1,813 UC patients		Hospital costs, LOS	No difference in total variable costs ( $p=0.78$ ) Lower (~10%) daily variable costs for PC than UC ( $p=0.03$ ) Larger proportional cost savings per day for PC where LOS is greater
(28)	Hanson et al., 2008	Tertiary academic medical center ----- Palliative Care Consultation Service (PCCS)	Cohort	104 PC patients 1,813 UC patients		Hospital costs, LOS	No difference in total variable costs ( $p=0.78$ ) Lower (~10%) daily variable costs for PC than UC ( $p=0.03$ ) Larger proportional cost savings per day for PC where LOS is greater

(continued)

TABLE 2. (CONTINUED)

Ref #	Study	Hospital(s) Team label	Design	Sample size Intervention/control	Principal diagnosis <sup>a</sup>	Outcomes of interest	Key findings
(29)	Morrison et al., 2008	Five community hospitals & three academic medical centers ----- Palliative Care Consultation Team (PCCT)	Cohort	Live discharges 2630 PC patients 18,427 UC patients Hospital deaths 2278 PC patients 2124 UC patients	Live discharge Cancer 29% Infection 4% Cardiovascular 19% Pulmonary 15% Gastrointestinal 7% Genitourinary 4% Other 22%  Hospital death Cancer 19% Infection 11% Cardiovascular 24% Pulmonary 18% Gastrointestinal 9% Genitourinary 4% Other 14%	Hospital costs	Live discharges Lower total costs (~14%; $p=0.02$ ), total costs per day (~19%; $p<0.001$ ), total direct costs (~15%; $p=0.004$ ), direct costs per day (~21%; $p<0.001$ ) for PC than UC  Hospital deaths Lower total costs (~18%; $p=0.001$ ), total costs per day (~22%; $p<0.001$ ), total direct costs (~22%; $p=0.003$ ), direct costs per day (~25%; $p<0.001$ ) for PC than UC
(30)	Penrod et al., 2010	Five Veterans Administration (VA) facilities ----- Palliative Care Consultation Team (PCCT)	Cohort	606 PC patients 2715 UC patients	Cancer 62% <sup>e</sup> COPD 36% CHF 28% HIV/AIDS 3%	Hospital costs, ICU use	PC patients 44% less likely to be admitted to ICU Lower <sup>f</sup> daily direct costs for PC than UC ( $p<0.0001$ ) Pharmacy, laboratory, & nursing also lower; no difference for radiology
(31)	Morrison et al., 2011	A community hospital, two academic medical centers, and a safety-net hospital ----- Palliative Care Consultation Team (PCCT)	Cohort	Live discharges 290 PC patients 1427 UC patients Hospital deaths 185 PC patients 149 UC patients	Cancer 58% AIDS 2% CHF 12% COPD 2% Advanced liver disease 19% Prolonged ICU stay 6.9%	Hospital costs, ICU use, LOS	Live discharges Lower total costs (~11%; $p<0.05$ ), total costs per day (~18%; $p<0.001$ ) for PC than UC Lower laboratory (~16%) & imaging (~13%) costs though not statistically significant Slightly higher ICU LOS but significantly lower (~42%; $p<0.001$ ) ICU cost per admission for PC than UC  Hospital deaths Lower total costs (~11%; $p<0.05$ ), total costs per day (~9%; $p<0.01$ ) for PC than UC Lower pharmacy (~21%; $p<0.001$ ) for PC than UC; no difference for laboratory or imaging Lower ICU LOS (10.2 days against 13.8; $p<0.01$ ) for PC than UC; no significant cost difference

(continued)

TABLE 2. (CONTINUED)

Ref #	Study	Hospital(s) Team label	Design	Sample size Intervention/control	Principal diagnosis <sup>a</sup>	Outcomes of interest	Key findings
(33)	Whitford et al., 2013	Integrated medical center comprising two hospitals ----- Palliative Care Consult Service (PCCS)	Cohort	Live discharges 1177 PC patients 3531 UC patients Hospital deaths 300 PC patients 900 UC patients	Live discharge Infectious 8% Neoplasm 21% Endocrine 2% Nervous 3% Circulatory 30% Respiratory 16% Digestive 8% Musculoskeletal 9% Other 3%  <i>Hospital death</i> Infectious 4% Neoplasm 32% Endocrine 3% Nervous 4% Circulatory 23% Respiratory 10% Digestive 7% Musculoskeletal 3% Other 14%	Hospital costs, incorporating ICU costs	<i>Live discharges</i> Lower total costs (~5%; $p < 0.05$ ) for PC than UC  Lower procedure costs; higher evaluation, imaging, pharmacy costs for PC than UC (no % or $p$ value given)  <i>Hospital deaths</i> Lower total costs (~31%; $p < 0.05$ ) for PC than UC  Lower procedure, evaluation, imaging, laboratory, pharmacy costs for PC than UC (no % or $p$ value given)

<sup>a</sup>For PC group at time of consultation.

<sup>b</sup>There is inconsistency in reporting of cost difference as a percentage. Ciemins et al. use the cost of palliative care as the base cost in calculations, i.e.,  $[\% \Delta C = ((C_{PC} - C_{UC}) / C_{PC}) \times 100]$  while others (e.g., Hanson et al.) use the cost of usual care, i.e.,  $[\% \Delta C = ((C_{PC} - C_{UC}) / C_{UC}) \times 100]$ . In this table and throughout the text all  $\% \Delta C$  have been calculated using the latter method.

<sup>c</sup>Gade et al. report a diagnosis for 196 PC patients (=71.3%)

<sup>d</sup>Primary diagnoses for all PC patients in overall sample ( $n = 304$ ); authors do not report corresponding figures for sub-sample in economic analysis ( $n = 104$ ).

<sup>e</sup>Patients could have more than one advanced disease diagnosis; therefore does not add up to 100%.

<sup>f</sup>No UC cost given so not possible to calculate proportional saving.

PC, palliative care; UC, usual care; LOS, length of stay; ICU, intensive care unit; RCT, randomized controlled trial; MV, mechanical ventilation; CHF, congestive heart failure; MI, myocardial infarction; COPD, chronic obstructive pulmonary disease; ESRD, end-stage renal disease; HIV/AIDS, human immunodeficiency virus/acquired immune deficiency syndrome.

are differences in study design, setting, intervention and population. Formal meta-analysis is also prevented by differences in approach to expressing costs; outcomes of interest are variously direct, variable and total costs, *per diem* and *in toto*.

Studies that report costs from the hospital perspective find statistically significant savings through palliative care in the 9%–25% range.<sup>24,25,28,29,31</sup> The three studies that stratify by survivors and decedents report consistently higher costs for patients who died but an inconsistent treatment effect on costs between the two groups; two studies find similar differences in proportional savings (11%–20%) with slightly higher treatment impact for decedents<sup>29,31</sup>; the other reports a large discrepancy with a 5% cost-saving from palliative care for survivors and 31% for decedents.<sup>33</sup>

Of the two studies reporting hospital charges, one reported mean daily charges around 7% lower for palliative care<sup>23</sup> and the other median total charges around 16% lower for palliative care.<sup>26</sup> The only study to take a postdischarge health costs perspective finds costs for palliative patients 32% lower than those for usual care patients over 6 months.<sup>27</sup> One study's reporting method precluded calculating a proportional difference.<sup>30</sup>

### Ancillary costs

Where ancillary costs are reported separately, the results are inconsistent. Where statistically significant differences have been identified, costs are typically lower for palliative care interventions, but differences are not always identified. A study<sup>24</sup> reports ancillary (laboratory and radiology) costs 43% lower and no difference in pharmacy; a larger follow-up study found differences in laboratory and pharmacy but not in imaging.<sup>30</sup> Another study<sup>29</sup> finds differences in pharmacy but not imaging; study<sup>31</sup> finds no difference in pharmacy. Another study<sup>33</sup> finds palliative care to be less costly across ancillary categories among patients who died, and different treatment effects by category for patients discharged alive.

### ICU costs

Of the six studies to report ICU use as an outcome of interest, the results have a clear pattern toward lower use among palliative patients.<sup>24,27,29,30,33</sup> One found no significant difference, possibly due to lack of power.<sup>28</sup>

### Discussion

The findings of this review demonstrate that inpatient specialist palliative care consultation teams are consistently found to be less costly than usual care comparators in the range 9%–25% for hospital costs, while one study estimated a 32% reduction for all health care costs over 6 months postdischarge. These differences are statistically significant.

However, methodology to date has implications for our understanding of the role that palliative care plays in enhancing value in health care, where value is defined as the relationship between quality and cost. In assessing current provision and validating new programs, payers and policy-makers are not only concerned with the immediate direct costs of providing hospital treatment. Specifically, questions remain as to whether reductions in hospital costs are passed on to other care settings or to family or informal caregivers,

the effect of palliative care teams on hospice expenditures, and the effect of palliative care teams on overall health care expenditures.<sup>34,35</sup> And ensuring that cost reduction does not reflect reduced quality of care is best achieved by a full cost-effectiveness analysis quantifying the relationship between cost effects and treatment efficacy.<sup>34</sup>

### Knowledge gaps

From first principles, cost-effectiveness analysis in health care is defined as a “comparative analysis of alternatives in terms of both costs and consequences.”<sup>22</sup>

With regard to costs, the focus has been on the hospital “silo.” Seven examine only costs to the hospital providing care.<sup>24,25,28–31,33</sup> while two use only hospital charges,<sup>23,26</sup> generally considered a poor approximation of hospital costs.<sup>34</sup> One study examines all health care costs post-discharge but not costs to patients, caregivers, or wider systems and society.<sup>27</sup>

With regard to consequences, there is no evidence base to date. No study has quantified the relationship between treatment efficacy and cost in a cost-effectiveness measure.

### What is needed?

Limitations to the current literature reflect practical real-world challenges in both the collection of data and the measurement of intangible outcomes such as satisfaction with care among a rapidly changing and extremely sick patient population.<sup>8</sup> However, with a clear pattern of hospital cost-saving using current methodology, it is timely to begin expanding the scope of economic evaluation in this field. The improvement of economic evaluation of palliative care teams requires that evaluators identify a greater proportion of relevant components in a full cost-effectiveness analysis, establish what is already known about these through existing datasets and published research, and considers the best way to measure and incorporate these in future.

### Components of cost analysis

There are four major categories of resource use for cost-effectiveness analysis (CEA), summarized in Table 3.<sup>35</sup>

As this summary makes clear, current economic evaluation has excluded key components of the cost effects of palliative care teams. Increasing the scope and thus reliability of economic evaluation of palliative care teams requires addressing these shortfalls.

First, future studies need to expand their perspective in examining health care resources beyond the perspective of direct hospital costs. These studies need to incorporate all relevant health care costs paid by patients, their families, and other payers, including pharmacy, and formal caregivers, and incorporate all disease-relevant system costs (“total spend”) following the initial intervention, both to hospitals and the health system, and to patients, families, and other payers.

A full cost-effectiveness analysis would examine and incorporate non-health care system costs, such as hours lost from work, caregiver comorbidity, financial consequences of serious illness to families, and patient and family caregiver time. As our review shows, no evaluation of in-hospital consultation teams has included these costs. Given the lack of

TABLE 3. COMPONENTS BELONGING IN THE NUMERATOR OF A COST-EFFECTIVENESS ANALYSIS<sup>34</sup>

<i>Cost component</i>	<i>Use in evaluation of palliative care teams</i>
Health care resources: <b>The costs</b> of tests, drugs, supplies, health care personnel and medical facilities, in providing intervention and in all subsequent interventions relevant to the disease or condition.	Health care resources have been partially included in the evaluations of palliative care teams to date: nine studies have used hospital costs only; Gade et al. <sup>27</sup> incorporates all formal health care costs for a 6-month period. Future studies therefore need to expand their perspective in examining health care resources: Broaden perspective beyond hospital costs to incorporate all relevant health care costs paid by patients, their families and other payers, including pharmacy, formal caregivers. Lengthen perspective beyond initial hospital stay to incorporate all disease-relevant system costs following the initial intervention, both to hospitals and the health system, and to patients, families and other payers.
Non-health care resources: <b>The costs</b> of other consumption entailed in the intervention and follow-up, e.g., transport to and from hospital; child care bills while a parent receives treatment	Non-health care resources were not included in the evaluations of palliative care teams to date. There is no established literature on this area to provide indicative magnitudes of these costs and, by definition, there is no central dataset. It seems likely that these can only be measured and incorporated in CEA through well-designed original primary research projects.
Patient time: <b>Time expended by the</b> patient seeking, participating in, and undergoing an intervention	Patient time costs were not included in the evaluations of palliative care teams to date. There is only a limited literature on this area to estimate the magnitude of these costs. It seems likely that these can only be measured and incorporated in CEA through well-designed original primary research projects.
Informal caregiver time: <b>Unpaid time</b> spent by family members or volunteers to provide homecare	Informal caregiver time costs were not included in the evaluations of palliative care teams to date. There is only a limited literature on this area to estimate the magnitude of these costs. It seems likely that these can only be measured and incorporated in CEA through well-designed original primary research projects.

CEA, cost-effectiveness analysis.

routine data collection in these domains, addressing these knowledge deficits may be best addressed by future primary research incorporating these domains in design.

Where future analysis remains focused on cost from the hospital perspective, our review highlights two particular priorities. First, studies to date have not analyzed in detail patient-level determinants of resource use. But factors such as socioeconomic status, functionality, and diagnosis may determine a high proportion of hospital costs in providing care to patients with serious illness.<sup>17,36,37</sup> Identifying relevant patient-level factors may offer new and valuable information for understanding variations in cost and so delivering care that is both more appropriate to patient needs and less resource-intensive. However, few studies in any setting have attempted this.<sup>38,39</sup> Second, the literature to date is skewed toward patients near end of life; as palliative treatment is increasingly introduced earlier in the care trajectory, it is important to develop evidence on treatment effects for patient groups with longer life expectancy at the time of consultation.

Future analysis will also be helped by more detailed cost reporting. Recent studies have tended to report both direct and total costs, *per diem* and *in toto*. This approach, alongside a definition of what each category comprises and how the figures were reached, is the best way to enable formal comparison and statistical analysis of results in future as well as to improve understanding of the data under discussion.

### **Approaches to estimating effectiveness**

There is no consensus on methodology for measuring effectiveness in the economic evaluation of palliative care.

Standardized guidelines for health economics research in the United States identify the quality-adjusted life year (QALY) as the fundamental outcome measurement for all evaluations.<sup>35</sup> However, equivalent guidelines specifically for palliative care have resisted this position.<sup>8,40</sup> The QALY approach has been criticized as inappropriate for patients with serious illness and is an ongoing subject of debate among economists in this field.<sup>41–43</sup>

Evaluators must make their own decision in research design to identify the contextually appropriate measures of physiological and health-related quality of life (HRQL) effects to be incorporated in cost-effectiveness analysis. Given the emerging state of the field, initial approaches do not need to be methodologically complex to make a substantial contribution. An example of a simple approach was illustrated in a U.K. study of short-term palliative care for multiple sclerosis.<sup>44</sup> The authors generated two cost-effectiveness planes, plotting the relationship of costs with patient outcomes (as measured by Palliative Care Outcome Scale [POS]-8) and caregiver burden (using Zaret Caregiver Burden [ZBI]-12).

In combining cost and effectiveness analysis for the same patient group the authors present more thorough and robust evidence to compare the impact of an intervention and a

comparator. This ought to be the goal of an increasing number of studies in future.

## Conclusion

The published evidence shows a clear pattern of specialist inpatient palliative care consultation teams reducing hospital costs. This finding is consistent with other reviews of the positive impact of palliative care programs on multiple outcomes across a range of settings.

By methodological norms in economic evaluation, the evidence base has been generated using a narrow approach. These limitations are defensible given practical challenges and available data but, with a clear pattern of cost saving using current methodology, it is timely to begin expanding the scope of economic evaluation in this field. The evidence now suggests that specialist inpatient palliative care both reduces costs and improves patient outcomes. Unifying this evidence in robust cost-effectiveness analysis will strengthen our understanding of the role that palliative care plays in enhancing value in health care.

There is a consensus on the appropriate approach to measuring costs, and this paper identifies the relevant domains. There is no consensus on the appropriate approach to measuring outcomes, but it ought to be possible to generate evidence using different approaches and so strengthen the evidence base amidst methodological debate. Given the lack of routine data collection in these domains, addressing knowledge deficits may be best addressed by future primary research.

Where future analysis remains focused on cost from the hospital perspective, research priorities should include the patient-level determinants of cost difference between palliative and usual care, and the economic impact of treatments earlier in the care trajectory.

## Author Disclosure Statement

No competing financial interests exist.

## References

- Center to Advance Palliative Care: Analysis of U.S. Hospital Palliative Care Programs 2010 Snapshot. 2010. [www.capc.org/news-and-events/releases/analysis-of-us-hospital-palliative-care-programs-2010-snapshot.pdf/file\\_view](http://www.capc.org/news-and-events/releases/analysis-of-us-hospital-palliative-care-programs-2010-snapshot.pdf/file_view) (Last accessed June 13, 2014).
- Davies E, Higginson I: *The Solid Facts: Palliative Care*. Copenhagen: World Health Organization, Regional Office for Europe, 2004.
- Davies E, Higginson I: *Better Palliative Care for Older People*. Copenhagen: World Health Organization, Regional Office for Europe, 2004.
- Goldsmith B, Dietrich J, Du Q, Morrison RS: Variability in access to hospital palliative care in the United States. *J Palliat Med* 2008;11:1094–1102.
- Meier DE: Increased access to palliative care and hospice services: Opportunities to improve value in health care. *Milbank Q* 2011;89:343–380.
- Goldstein NE, Morrison RS: The intersection between geriatrics and palliative care: A call for a new research agenda. *J Am Geriatr Soc* 2005;53:1593–1598.
- Gelfman LP, Du Q, Morrison RS: An update: NIH research funding for palliative medicine 2006 to 2010. *J Palliat Med* 2013;16:125–129.
- Higginson IJ, Evans CJ, Grande G, Preston N, Morgan M, McCrone P, Lewis P, Fayers P, Harding R, Hotopf M, Murray SA, Benalia H, Gysels M, Farquhar M, Todd C; MORECare: Evaluating complex interventions in end of life care: The MORECare statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews. *BMC Med* 2013;11:111.
- Meier DE, Beresford L: Palliative care cost research can help other palliative care programs make their case. *J Palliat Med* 2009;12:15–20.
- Smith TJ, Hillner BE: Bending the cost curve in cancer care. *N Engl J Med* 2011;364:2060–2065.
- Gomes B, Harding R, Foley KM, Higginson IJ: Optimal approaches to the health economics of palliative care: Report of an international think tank. *J Pain Symptom Manage* 2009;38:4–10.
- Higginson IJ, Finlay I, Goodwin DM, Cook AM, Hood K, Edwards AG, Douglas HR, Norman CE: Do hospital-based palliative teams improve care for patients or families at the end of life? *J Pain Symptom Manage* 2002;23:96–106.
- Douglas HR, Halliday D, Normand C, Corner J, Bath P, Beech N, Clark D, Hughes P, Marples R, Seymour J, Skilbeck J, Webb T: Economic evaluation of specialist cancer and palliative nursing: A literature review. *Int J Palliat Nurs* 2003;9:424–428.
- Higginson IJ, Finlay IG, Goodwin DM, Hood K, Edwards AG, Cook A, Douglas HR, Normand CE: Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage* 2003;25:150–168.
- Zimmermann C, Riechelmann R, Krzyzanowska M, Rodin G, Tannock I: Effectiveness of specialized palliative care: A systematic review. *JAMA* 2008;299:1698–1709.
- Higginson IJ, Evans CJ: What is the evidence that palliative care teams improve outcomes for cancer patients and their families? *Cancer J* 2010;16:423–435.
- Simoens S, Kuttan B, Keirse E, Berghe PV, Beguin C, Desmedt M, Deveugele M, Léonard C, Paulus D, Menten J: The costs of treating terminal patients. *J Pain Symptom Manage* 2010;40:436–448.
- El-Jawahri A, Greer JA, Temel JS: Does palliative care improve outcomes for patients with incurable illness? A review of the evidence. *J Support Oncol* 2011;9:87–94.
- Smith S, Brick A, O'Hara S, Normand C: Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliat Med* 2014;28:130–150.
- Centre for Reviews and Dissemination, University of York: *Systematic Reviews: CRD's Guidance for Undertaking Reviews in Health Care*. York: CRD, University of York, 2009.
- Smith TJ, Cassel JB: Cost and non-clinical outcomes of palliative care. *J Pain Symptom Manage* 2009;38:32–44.
- Drummond MF, Jefferson TO: Guidelines for authors and peer reviewers of economic submissions to the BMJ. The BMJ Economic Evaluation Working Party. *BMJ* 1996;313:275–283.
- Cowan JD: Hospital charges for a community inpatient palliative care program. *Am J Hosp Palliat Care* 2004;21:177–190.
- Penrod JD, Deb P, Luhrs C, Dellenbaugh C, Zhu CW, Hochman T, Maciejewski ML, Granieri E, Morrison RS: Cost and utilization outcomes of patients receiving hospital-based palliative care consultation. *J Palliat Med* 2006;9:855–860.



25. Ciemins EL, Blum L, Nunley M, Lasher A, Newman JM: The economic and clinical impact of an inpatient palliative care consultation service: A multifaceted approach. *J Palliat Med* 2007;10:1347–1355.
26. Bendaly EA, Groves J, Juliar B, Gramelspacher GP: Financial impact of palliative care consultation in a public hospital. *J Palliat Med* 2008;11:1304–1308.
27. Gade G, Venohr I, Conner D, McGrady K, Beane J, Richardson RH, Williams MP, Liberson M, Blum M, Della Penna R: Impact of an inpatient palliative care team: A randomized control trial. *J Palliat Med* 2008;11:180–190.
28. Hanson LC, Usher B, Spragens L, Bernard S: Clinical and economic impact of palliative care consultation. *J Pain Symptom Manage* 2008;35:340–346.
29. Morrison RS, Penrod JD, Cassel JB, Caust-Ellenbogen M, Litke A, Spragens L, Meier DE; Palliative Care Leadership Centers' Outcomes Group: Cost savings associated with US hospital palliative care consultation programs. *Arch Intern Med* 2008;168:1783–1790.
30. Penrod JD, Deb P, Dellenbaugh C, Burgess JF Jr, Zhu CW, Christiansen CL, Luhrs CA, Cortez T, Livote E, Allen V, Morrison RS: Hospital-based palliative care consultation: Effects on hospital cost. *J Palliat Med* 2010;13:973–979.
31. Morrison RS, Dietrich J, Ladwig S, Quill T, Sacco J, Tangeman J, Meier DE: Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. *Health Aff (Millwood)* 2011;30:454–463.
32. Economic and Social Research Institute (ESRI): Clinical Coding. February 16, 2012. [www.esri.ie/health\\_information/hipe/clinical\\_coding/](http://www.esri.ie/health_information/hipe/clinical_coding/) (Last accessed June 13, 2014).
33. Whitford K, Shah ND, Moriarty J, Branda M, Thorsteinsdottir B: Impact of a palliative care consult service. *Am J Hosp Palliat Care* 2014;31:175–182.
34. Drummond MF, Sculpher MJ, Torrance GW, O'Brien BJ, Stoddart GL: *Methods for the Economic Evaluation of Health Care Programmes*, 3rd ed. Oxford: Oxford University Press, 2005.
35. Gold MR: *Cost-Effectiveness in Health and Medicine*. New York/Oxford: Oxford University Press, 1996.
36. Tibi-Levy Y, Le Vaillant M, de Pouvourville G: Determinants of resource utilization in four palliative care units. *Palliat Med* 2006;20:95–106.
37. Gomez-Batiste X, Tuca A, Corrales E, Porta-Sales J, Amor M, Espinosa J, Borràs JM, de la Mata I, Castellsagué X; Grupo de Evaluación-SECPAL: Resource consumption and costs of palliative care services in Spain: A multicenter prospective study. *J Pain Symptom Manage* 2006;31:522–532.
38. Kelley AS, Ettner SL, Morrison RS, Du Q, Wenger NS, Sarkisian CA: Determinants of medical expenditures in the last 6 months of life. *Ann Intern Med* 2011;154:235–242.
39. Groeneveld I, Murtagh F, Kaloki Y, Bausewein C, Higginson I: Determinants of Healthcare Costs in the Last Year of Life. The Annual Assembly of American Academy of Hospice and Palliative Medicine & Hospice and Palliative Nurses Association; New Orleans, LA: March 14, 2013.
40. Preston NJ, Short V, Hollingworth W, McCrone P, Grande G, Evans C, et al. MORECare research methods guidance development: Recommendations for health economic evaluation in palliative and end of life care research [abstract]. *Palliat Med* 2012;26:541.
41. Normand C: Measuring outcomes in palliative care: Limitations of QALYs and the road to PalYs. *J Pain Symptom Manage* 2009;38:27–31.
42. Round J: Is a QALY still a QALY at the end of life? *J Health Econ* 2012;31:521–527.
43. Normand C: Setting priorities in and for end-of-life care: Challenges in the application of economic evaluation. *Health Econ Policy Law* 2012;7:431–439.
44. Higginson IJ, McCrone P, Hart SR, Burman R, Silber E, Edmonds PM: Is short-term palliative care cost-effective in multiple sclerosis? A randomized phase II trial. *J Pain Symptom Manage* 2009;38:816–826.

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# A review of Specialist Palliative Care provision and access across London

## Mapping the capital

September 2015



A joint report by



Care and support  
through terminal illness



## Acknowledgements

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This report has been jointly produced by the London Cancer Alliance, PallE8 and Marie Curie in collaboration with Specialist Palliative Care providers across London.

The **London Cancer Alliance** (LCA), formed in 2012, seeks to improve clinical outcomes for cancer patients, the experience of cancer patients and reduce variation in service provision for cancer patients across South and West London. The LCA's palliative care group was also formed in 2012, as an important cross cutting pathway to inform all tumour specific work across the LCA. The palliative care group aims to improve the access, experience and outcomes for patients requiring palliative care, irrespective of their diagnosis, across West and South London. The membership of the group brings together specialist NHS and voluntary sector expertise from primary, secondary and tertiary care, as well as service users, to enable the development of high quality patient-centred care. The group developed the methodology used in the mapping exercise that informs this report.

**PallE8** is a clinically-led expert reference group for specialist palliative and end of life care for adults and children covering North Central London, North East London and West Essex. PallE8's membership includes all providers of specialist palliative and end of life care from across hospital, community and hospice teams within the region.

**Marie Curie** is a registered charitable organisation in the UK, providing care and support to people with terminal illnesses and their families. Marie Curie also takes a leading role in campaigning on behalf of people living with a terminal illness and their families, to make sure they can access the high quality care they need, when they need it most.

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# Appendices

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**All the appendices are available as a separate document.**

**Appendix 1:** National Council for Palliative Care definitions of Specialist Palliative Care services

**Appendix 2:** CCG level demographics

**Appendix 3:** Number of individuals seen one or more times in 2013/14 by service/provider for each CCG and percentage distribution

**Appendix 4:** Service availability tables

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**Appendix 6:** Proxy ratio for patients seen by community SPC and hospice in-patient SPC bed services to 'need'

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# 1: Executive summary

The aim of this report is to provide more information on Specialist Palliative Care (SPC) provision in London. It is hoped that the data analysis in this report will be useful to both commissioners and SPC providers in their plans to improve care and reduce inequity in the quality of care for patients with life-limiting illnesses.

## 1.1 Background

For people with life-limiting illnesses and their family/carers, poor provision of services and support can add to the stress and confusion of an already-difficult time. Conversely, the right care and support at the right time can make all the difference.

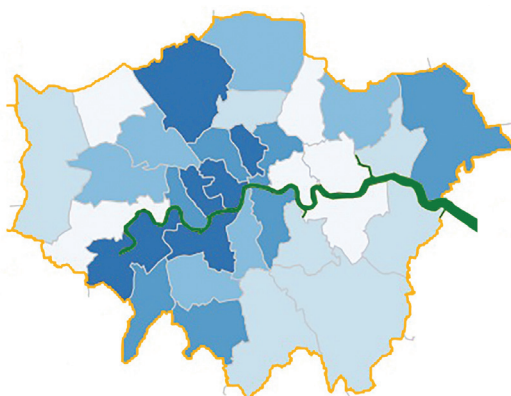
London contains some of the country's best care for people with life-limiting conditions but also some of the worst. For example, the latest national VOICES survey of the bereaved (2012), which covers the care of people within their last three months of life provided by SPC and other services, rated the Islington Clinical Commissioning Group (CCG) area second for quality in the whole of England whereas the Newham CCG area emerged as the worst.

Specialist Palliative Care (SPC) is defined as "the active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support"<sup>1</sup>. SPC services should be available to all patients with cancer and non-malignant diseases on the basis of need.

To understand more about the provision of SPC in London, the palliative care group of the London Cancer Alliance (LCA) mapped SPC services across West and South London soon after its formation in 2012. A year later its counterpart, PallE8, used the same approach to map SPC services in North and East London.

**Figure 1: Huge variation in overall quality of end of life care across London**

The second best rated CCG in the UK is in London; and so is the worst.



% rating quality of care as outstanding or excellent

- 26.5 – 32.8
- 32.9 – 35.2
- 35.3 – 37.1
- 37.2 – 45.1
- 45.2 – 56.3

Reference:  
Marie Curie Atlas (source: combined data from the ONS Survey of Bereaved People VOICES, 2011-12)

1 National Council for Palliative Care. Commissioning guidance for specialist palliative care: Helping to deliver commissioning objectives, 2012.

Now these two organisations, in collaboration with Marie Curie, have worked together to provide an updated picture of SPC provision across the whole of the capital, making such complete information available for the first time. This report is a synopsis of their joint findings and it includes recommendations for the commissioners of these critical services.

The report demonstrates that SPC services are provided at home, in hospital and in hospices across London, in weekday working hours. In keeping with the national picture, our SPC services see a disproportionate number of people with cancer, although the data we have analysed shows that more patients with non-malignant disease are accessing SPC services over time. Out-of-hours availability of SPC services has improved in the two years between the mapping exercises in South and West London (LCA areas) and in a small number of London CCG areas, this out-of-hours availability goes beyond the requirements of national guidance. In contrast, some deterioration in service availability was observed in North East and North Central areas.

Despite this, SPC services across London are still not fully meeting the out-of-hours service availability mandated by NICE guidance in 2004. These differences exist even within individual CCG areas, with some patients experiencing different levels of SPC access depending on where they live in the borough.

The London Cancer Alliance, PallE8 and Marie Curie have worked in partnership on this report. Our collective goal is to ensure that everyone, regardless of their condition, where they live or the services they use, gets the best possible specialist palliative care whenever they need it.

## 1.2 Methods

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A template was designed by the London Cancer Alliance Palliative Care Group, building on the audit template design from 2012. This expanded on the established National Council for Palliative Care minimum data set to collect not only essential numerical, demographic and

diagnostic information for patients seen over the most recent 12-month period, but also the types and availability of SPC services provided across London.

Information was also collected on providers' staffing levels at one specified time point within the year and their use of clinical outcome measures.

The template was completed by all 50 adult SPC providers in London, as well as by paediatric SPC services in North Central and North East London, and covered services in hospitals, hospices and the community. The results were correlated, both by each organisation and by the 32 CCGs in the capital. Data was checked and cleaned, with detailed checking with providers for any missing or obviously incorrect data (including outliers), then provided back to each organisation in report format for final checking before being accepted as correct.

## 1.3 Key findings

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- The report demonstrates that SPC services are provided at home, in hospital and in hospices across London, in weekday working hours.
- There was noticeable variation in out-of-hours availability of both hospital SPC and community SPC services across London in 2013/14. Availability of SPC services outside Monday to Friday, 9am to 5pm was a quality standard applied by NICE in 2004 for the specialist palliative care of cancer patients and this has now been endorsed by the latest government guidance for the care of all dying patients<sup>2</sup>.
- SPC service providers across South and West London (ie the London Cancer Alliance areas) have improved their out-of-hours service availability somewhat since the 2012 audit; in contrast, some deterioration in service availability was observed in North East and North Central areas.

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<sup>2</sup> Leadership Alliance for the Care of Dying People. One Chance to Get it Right. London: UK Government, 2014: 27, para.46.

- London SPC hospital advisory, community and hospice in-patient services saw more non-cancer patients in 2013/14 than national averages. The proportion of non-malignant referrals has also increased on average from a similar 2012 exercise. However, given that non-cancer deaths accounted for 71% of all deaths in 2014, this report indicates that London still has an unmet need concerning non-cancer patients accessing SPC services.
- The numbers of cancer deaths in each CCG area are a proxy for SPC need. It was found that, across London in 2013/14, there was a large variation in the ratio of patients who died with cancer to those who were seen by community SPC services. The same was true for hospice in-patient services. This variation should be further explored to understand the reasons underlying it.
- The report highlights variation in service provision within some CCGs with multiple providers.
- The data demonstrates clear variations between CCGs in the ratio of patients seen by community SPC services to patients seen in hospice in-patient SPC units, which again should be further explored to understand these differences.

## **1.4 Key recommendations for CCG commissioners**

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- Commissioners should be clear on SPC provision in their area, the characteristics of the services delivered and how each service has been tailored to meet the needs of their local population.
- Commissioners should improve collaboration with providers to ensure equity of SPC access and provision for all CCG residents.
- Both hospital and community SPC teams across London require further support to fully achieve the 2004 NICE quality standard for cancer. As a minimum, SPC services in hospital and the community should be supported to provide face-to-face visiting from 9am to 5pm, seven days a week, and telephone advice 24 hours a day, seven days a week.
- Commissioners should review staffing levels with their local SPC services to ensure they are in line with national recommendations.
- Commissioners should be aware of how their CCG performs against proxy measures for SPC need and outlying SPC services should be supported to understand why they differ from other services.
- It is recommended that CCGs from across London work with their local clinicians, patient groups, the voluntary sector, social care, public health organisations and local SPC services to understand need. The CCGs can then develop, fund adequately and evaluate appropriate, cost-effective SPC services. These services should meet the need for symptom control and psychosocial support of patients with advanced malignant or non-malignant diseases and their family/carer.



- When addressing local SPC needs, commissioners are asked to note that previous national guidance focused on the cancer patient population (NICE 2004), which often guided SPC service development at that time. Recent relevant guidance (eg NICE EOLC *Quality Standards*, 2011; *One chance to get it right*, 2014) has highlighted that SPC should be fully accessible for all adult patients with relevant complex needs, irrespective of their diagnosis. Therefore, commissioners may need to review their local SPC service capacity to accommodate this likely increase in demand.
- Given the generally ageing population and the likely increase over time in the percentage of people over the age of 65 from a Black, Asian and minority ethnic (BAME) background, it is recommended that CCGs look at their demographic projections and work accordingly with their local clinicians, community groups and their SPC services to develop, fund and evaluate appropriate, cost-effective services.
- While data quality for community SPC services and hospice in-patient services are generally robust, challenges around data quality for hospice day care services in particular and outpatient services mean that data related to these services would need to be considered with caution.
- It is difficult for us to make robust conclusions on equity of access to services on the basis of patients' BAME status. This is because the BAME status of patients accessing SPC services has been recorded with variable levels of quality, and the ethnic breakdown of BAME patients accessing those services does not necessarily correlate with the overall ethnic breakdown of a CCG which covers all age groups (given the average older age of SPC patients).

## 1.5 Key considerations

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- This report covers the provision of SPC services in London and not the more general end of life care provided by in-patient acute wards, GPs, community nursing teams and care homes.
- Due to the lack of nationally accepted measures of SPC patient need, outcome or service quality, caution must be exercised when interpreting variances as best practice has not been defined.
- Data provided in the appendices only highlight services where 10 or more individuals were seen in that year. Furthermore, there are a number of patients who were not classified by CCG and this will have an impact on the accuracy of the data.

# 2: Scope

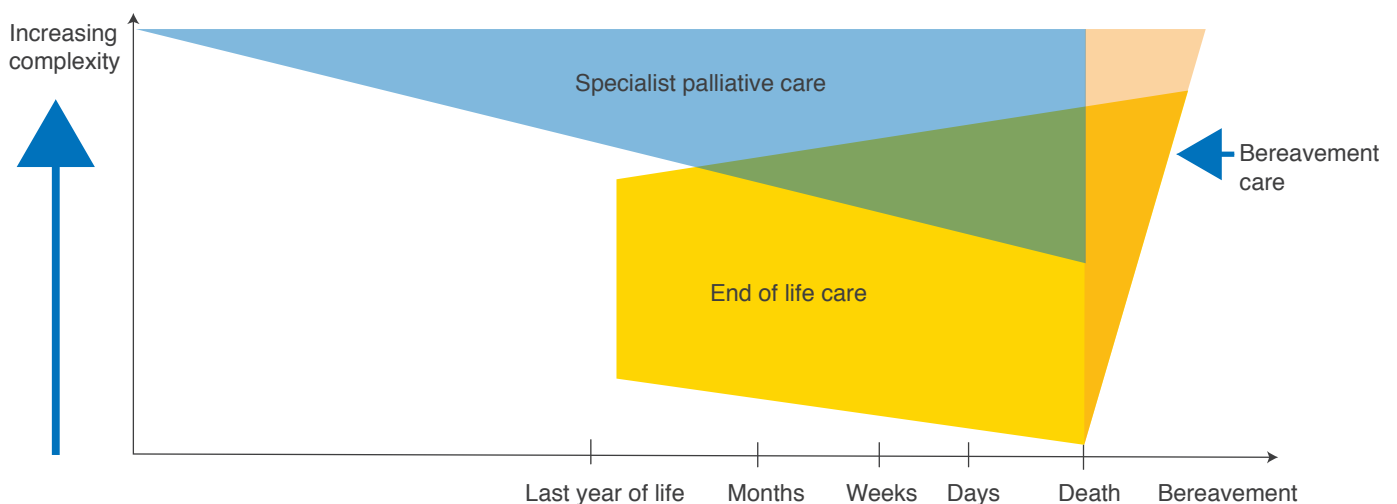
The scope of this report covers the provision of Specialist Palliative Care (SPC) services in London. SPC is defined as “the active, total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support”<sup>3</sup>.

**“We want professionals to recognise this is often a traumatic period in our lives and a memory of a good death can support us as carers to feel consoled after they have died, whereas the memory of a death involving unnecessary suffering can often be a long-term painful memory.”**

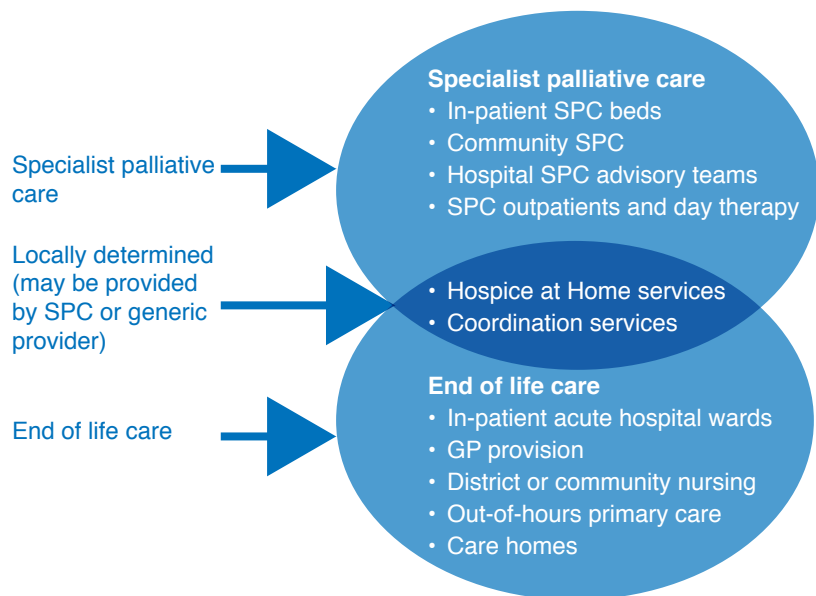
Brian Andrews, Chair of Lay Representatives, Board of the Pan-London End of Life Alliance

It is important to highlight that SPC is core to optimal end of life care delivery, although the majority of end of life care will be provided by generalists. Figure 2 below demonstrates the relationship between SPC and more general end of life care, and highlights the point that SPC tends to benefit more complex cases. Figure 3, on the next page, outlines the overlap in services delivered by SPC providers, recognising that some SPC providers also lead on end of life care locally. The categories of SPC service types covered by this report follow the National Council for Palliative Care’s definitions detailed in Appendix 1. SPC, unlike most of core healthcare delivery in the UK, is co-funded by the NHS and third sector. This has resulted in service development that is being driven as much, if not more, by individual providers rather than a national strategy.

**Figure 2: Relationship between SPC and more general end of life care**



3 National Council for Palliative Care. *Commissioning guidance for specialist palliative care: Helping to deliver commissioning objectives*, 2012.



**Figure 3: Outline of service types delivered by SPC compared to more general end of life care.**

At present there are no nationally accepted measures of patient need, outcomes or service quality for SPC, although the Palliative Care Funding Review<sup>4</sup>, the upcoming NICE guidance<sup>5</sup> and the Peer Review of Specialist Palliative Care Services<sup>6</sup> have all considered the matter. By 2017, Public Health England aims to collect a national individual-level dataset from specialist palliative care services including demographic details, activity information and patient outcomes data.

The aim of this report is to provide more information on SPC provision in London. It is hoped that the data analysis in this report will be useful to both commissioners and SPC providers in their plans to improve care for patients with life-limiting illnesses and reduce inequity in their quality of care. However, because we are not measuring outcomes – due to the lack of nationally accepted measures of SPC patient need, outcomes or service quality – caution must be exercised when interpreting variances, as we cannot say what represents best practice.

It is worth noting that this report does not cover some services operating outside of London that support patients living within CCGs on the outskirts of London.

This report focuses on measuring a level of service activity as opposed to patient outcomes. However, it is also worth noting that there is comparative data from the VOICES and FAMCARE bereavement surveys which demonstrate that bereaved relatives report higher levels of satisfaction from SPC services than from non-SPC services<sup>7</sup>.

**Table 1: Outline of data that has been reviewed for this report and what is out of scope**

What is covered	What is out of scope
<ul style="list-style-type: none"> <li>All clinical services for SPC for adults across all settings in London, and paediatric palliative care across NE and NC London areas</li> <li>NHS and non-NHS service delivery</li> <li>Measures of service activity (individual patient counts only)</li> <li>Service access</li> <li>Patient specific characteristics – diagnosis (cancer/non-cancer), age bands and ethnicity, if recorded</li> </ul>	<ul style="list-style-type: none"> <li>Measures of need</li> <li>Measures of quality</li> <li>Patient outcome measures</li> <li>Other service activity – education, governance and research (SPC clinical services provide substantial wider education, clinical governance and research services)</li> </ul>

4 Hughes-Hallett et al. *Funding the Right Care and Support for Everyone – Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review*, 2011.  
 5 NICE guidance for care of the dying adult, due to be published in December 2015.  
 6 National Cancer Peer Review-National Cancer Action Team. *National Cancer Peer Review Programme Manual for Cancer Services: Specialist Palliative Care Measures*, 2012.  
 7 Davies A, Peel T and Cox, S. *Bereaved relatives' satisfaction with the end of life care provided by specialist palliative care services in hospices, home, and hospitals: a service evaluation* by the Association for Palliative Medicine of Great Britain and Ireland, 2014. Awaiting publication.

# 3: Who are the populations we are trying to deliver services to?

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## 3.1 Need-based rather than diagnosis-based approach

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The World Health Organisation and National Council for Palliative Care definitions of SPC emphasise that SPC benefits patients on the basis of need rather than diagnosis.

However, defining the population in need of SPC presents a significant challenge, as unlike cancer populations, this group is not currently clearly defined. Therefore, while the number of cancer deaths can be used as a relative proxy measure for SPC need, it does not accurately reflect the true population need, especially considering only 29% of adult deaths in 2014 were from cancer<sup>8</sup>.

## 3.2 Cancer versus non-cancer need

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The roots of the modern hospice and palliative care movements developed in response to the needs of people with cancer. Consequently, until recently, palliative care services mainly focused on identifying, assessing and supporting cancer patients, with limited focus on identifying the needs of non-cancer patients. As a result, referral to SPC and coordination of services is not as well developed for people with non-malignant diseases.

Over the last decade, there has been an increasing recognition within national policy and clinical guidance of the unmet palliative care needs of patients with non-malignant diseases<sup>9</sup>. This recognition was based on data demonstrating that the needs of patients with a non-malignant advanced disease (eg heart failure, COPD, MND and dementia) are as significant and varied as those of cancer patients<sup>10,11</sup>. This research also estimated that 16.8% of patients with advanced non-malignant disease would benefit from SPC services.

A further study reported that patients with non-cancer conditions often experience community palliative care as inadequate and in need of planning and innovation<sup>12</sup>.

In addition, a recent systematic review concluded that 'it is crucial that palliative care teams clearly define the roles of their professionals and increase capacity to deal with the uncertainty of non-cancer illness trajectories through effective interdisciplinary work'<sup>13</sup>.

This suggests that SPC services will need further resourcing to address the unmet need of the non-cancer population, although it is by no means certain that the needs of the cancer population are being met either.

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8 National Council for Palliative Care. The end of life care strategy: New ambitions, 2014.

9 Department of Health. End of Life Care Strategy, 2008.

10 Addington-Hall JM. Specialist palliative care in non-malignant disease, *Palliative Medicine* 1998; 12: 417–427

11 Gomes B, Higginson IJ. Where people die (1974 – 2030): past trends, future projections and implications for care, *Palliative Medicine*, 22, 1, 33 – 41, 2008.

12 Addington-Hall JM, Hunt KJ. Non-cancer patients as an under-served group. In: Cohen J, Deliens L, eds. *A public health perspective on end of life care*. Oxford: Oxford University Press, 2012:151–9.

13 Oishi A, Murtagh FE. The challenges of uncertainty and inter-professional collaboration in palliative care for non-cancer patients in the community: a systematic review of views from patients, carers and health-care professionals *Palliat Med* 2014;28:1081–98.

### 3.3 London demographics

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Current mortality figures for England show that around 451,000 people die per year, with the three leading causes of death consisting of cancer (29%), circulatory disease (28%) and respiratory disease (14%)<sup>14</sup>. Projections suggest that, by 2037, the mortality rate will rise by an additional 109,000 per year to 560,000 people each year<sup>15</sup>.

London CCG demographics are outlined in Appendix 2. It is clear there are significant local variations in demographics and deprivation across London, with numerous mobile, immigrant, multi-ethnic and homeless populations, as well as those who do not have English as their first language or are illiterate. It is likely that these factors will impact on access to SPC services<sup>16</sup>.

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14 Office of National Statistics. Mortality Statistics, 29 October 2014

15 Office of National Statistics. National population projections (NPPs), 2015.

16 Dixon et al. Equity in the Provision of Palliative Care in the UK: Review of Evidence, 2015.

# 4: Specialist Palliative Care services accessed by CCG

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## 4.1 Data analysis

The types of SPC provision available to adult residents of London's 32 CCGs have been identified, including who provides them and the number of patients who access each type of service (Appendix 3). It is not possible to say from the data whether appropriate numbers of patients are accessing specialist palliative care services in each CCG, but we have analysed this further in Chapter 6.

It should also be noted that it is possible that CCGs on the London borders will receive some service from providers outside the London Cancer Alliance or Palle8 areas. Non-London resident patients receiving services from the London providers were also included in the analysis.

### Hospice in-patient services

- All of London's CCGs have access to in-patient hospice beds. These are provided by a total of 15 organisations of which only four belong to the NHS, the remainder being charitably owned and largely charitably funded.

### Hospital services

- All the multi-speciality hospitals serving London have palliative care teams, and in all but one case, are funded directly by the NHS Trust concerned. The specialist centres, including The Royal Marsden, The Royal Brompton and Harefield, and Queen Square (this centre is covered by the CNWL UCLH SPC service) also have palliative care teams.
- Hospital teams mostly function in an advisory capacity to hospital clinicians in other specialties, who usually retain primary responsibility for their patient's care.

### Community services

Community SPC services are subject to much greater variability than hospice in-patient services, both in their design and their availability.

- Community specialist palliative care in this report refers to teams of palliative care clinical nurse specialists with palliative medicine specialist support. They can visit patients in their own homes as well as provide telephone advice. All CCGs have access to this type of service during weekday working hours; however, Appendix 5 reveals that the facilities available at other times vary considerably between providers.
- Palliative care day therapy services provide a range of creative and rehabilitation activities for community patients as well as the opportunity to maintain and renew social interactions. Day care is available in most CCGs but exceptions exist, eg in Waltham Forest.
- Numbers attending day services as a proportion of those receiving community SPC (assuming that those counted under day services also received community SPC) vary substantially, e.g. about one in 17 in Hounslow, one in 10 in West London, one in eight in Newham and one in four in Bromley. It is unclear whether these differences result from issues of capacity or of the practicality of reaching the centre concerned (we also need to be cautious in interpreting this data as data quality for day care services is likely to be poorer).

- Palliative care services may provide outpatient clinic facilities for patients fit enough to travel, sometimes in response to the need for a specific professional intervention, eg from a doctor or a social worker, or, alternatively, as a potentially more efficient use of nursing resources than making a home visit the basis of every face-to-face encounter.
- SPC outpatient facilities are provided in all but five of London CCG areas (Hounslow, Merton, Sutton, Haringey and Islington) but the number of patients involved tends to be small compared with those receiving usual community SPC.
- A small number of CCGs have Rapid Response or Care Coordination services. The absence of an identified Rapid Response service does not mean that no such facility exists, as most community SPC teams adjust the speed of their response to a referral according to its degree of clinical urgency.
- Care Coordination services bring together SPC provision with generic end of life support and social care.
- Most SPC hospice in-patient services provide lymphoedema management for their own patients, and both hospice in-patient and community services provide bereavement support following the deaths under their care. These types of care are occasionally available to clients not otherwise known to the provider. When these types of care are not listed for a particular CCG, it does not mean that they do not exist in that area but just that they do not come from a SPC provider.

In addition to these common forms of community provision, a range of other types of service have been developed at the initiative of individual providers, with or without local commissioning support. Most of these services are intended to either prevent hospice in-patient or hospital admission, or to facilitate discharge from such settings:

- Hospice at Home (H@H) provides extra hands-on nursing care to complement the statutory district nursing service and the usual advisory role of the palliative care clinical nurse specialist<sup>17</sup>.
- 13 CCGs have a H@H-type service from one or more of seven providers. Some of these services cater only for patients already known to the provider's usual community SPC team while others, eg the North London Hospice Palliative Care Support Service, receive referrals directly.
- The large variation in the ratio of patients receiving H@H input to the total number of patients receiving usual community SPC, from around 1:25 in Richmond, to 1:6 (a fairly typical figure) in Harrow, to 1:1.5 in Greenwich, presumably reflects differences between localities in models of provision as well as in resources.
- The reason for this in the case of hospital palliative care teams is clear. According to specialty and sometimes locality, a CCG's residents are likely to enter different hospitals and their palliative care needs during an admission are dealt with by the SPC team of the hospital involved.
- In relation to community services, the reason for multiple providers is historic. Areas served by particular community SPC teams were delineated under a previous phase of NHS organisation and, indeed, were often separate from it. They therefore have boundaries that often do not match those of today's CCGs. This can also apply to the catchment areas of hospice in-patient units, which are likely to extend across all or parts of more than one CCG.

### Multiple providers

The data indicates that there are numerous instances in which the same type of service for a single CCG is split between two or more providers (Appendix 3).

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<sup>17</sup> National Association for Hospice at Home.

- Of the 32 London CCGs, 19 have a single provider for SPC in-patient (ie hospice) services and 13 have a single provider for community SPC. For 12 CCGs, each type of service is provided by a single provider and, in 11 cases, this is the same provider for both service types.
- Other CCGs have up to four community SPC providers (eg Ealing, Camden) and three hospice in-patient providers (eg Islington, West London).
- The division of service between providers is rarely equal. In Brent, St Luke's Hospice and the Pembridge Palliative Care Unit respectively account for 49% and 47% of adult community SPC provision, but the remaining 4% is divided between two other providers. Likewise, St John's Hospice undertakes 49% of Westminster's hospice in-patient SPC but 37% is provided by the Pembridge unit and 14% by Trinity Hospice.
- It is unclear the extent to which multiple providers in a CCG overlap with each other and, if they do, who selects where a patient is referred to.

It is not necessarily either an advantage or a disadvantage to have multiple providers within a single CCG. However, the data for service availability in Appendix 5 reveals that community SPC services vary significantly in what they provide outside working hours.

Therefore, residents of individual CCGs can receive very different levels of community SPC support depending on the provider they are referred to (see Chapter 5). These inequities are not new and, in the areas where they exist, there is little evidence that the commissioning process has made effective progress in resolving them.

## 4.2 Recommendations for commissioners

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- Commissioners should be clear on SPC provision in their area, the characteristics of the services delivered and how each service has been tailored to meet the needs of their local population.
- Commissioners should improve collaboration with providers to ensure equity of SPC access and provision for all CCG residents.



# 5: Specialist Palliative Care community and hospital advisory service availability

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## 5.1 Data analysis

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The service availability data from the 2014 mapping exercise for hospital advisory services and community services was compared with similar data in both LCA and PallE8 areas from 2012 and 2013 respectively. This data (on availability of 24/7 telephone advice and a 7-day face-to-face visiting service, in the community and hospital SPC services) is shown in Appendix 4.

The availability of community SPC, in each CCG, regardless of who provides it, is shown in Appendix 5.

Hospice in-patient SPC services all provide face-to-face support seven days a week at all hours and therefore are not shown separately.

Availability of SPC services outside Monday to Friday, 9am to 5pm was a quality standard applied by NICE<sup>18</sup> in 2004 for the specialist palliative care of cancer patients. They specified the importance of provision of both telephone advice and face-to-face visiting.

*"The (SPC) team should be staffed to a level sufficient to undertake face-to-face visits to all people with cancer at home or in hospital, 09.00-17.00, seven days a week. In addition, there should be access to telephone advice at all times (24 hours seven days a week). This is considered a minimum level of service. Provision for bedside consultations in exceptional cases outside the hours of 09.00-17.00, seven days a week is also desirable."*

This quality standard has now been endorsed by the latest government guidance for the care of all dying patients<sup>19</sup>.

These recommendations are also echoed by:

- the NICE guidance for end of life care<sup>20</sup>
- Care Quality Commission<sup>21</sup>
- professional bodies in palliative and end of life care<sup>22</sup>

### **For hospital SPC services across London in 2013-14:**

- Only 9 of 30 services were able to provide seven-day visiting services.
- Four services do not provide telephone advice out of hours (Princess Alexandra Hospital, Barnet and Chase Farm Hospital Trust, North Middlesex Hospital and Whittington Hospital).
- Three services are providing a six-day visiting service.
- However, six services are providing face-to-face visiting all hours, which represents best practice (University Hospital Lewisham; King's College Hospital NHS Foundation Trust; Central and North West London – University College London Hospitals service; Central and North West London HCA Specialist Palliative Care Service; Royal Marsden NHS Foundation Trust; and Guy's and St Thomas' NHS Foundation Trust).

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18 NICE. Improving supportive and palliative care for adults with cancer, 2004.

19 Leadership Alliance for the Care of Dying People. One Chance to Get it Right. London: UK Government, 2014: 27, para.46.

20 NICE. Quality standard 10: Specialist Palliative Care (QS13), 2011.

21 Care Quality Commission supports new vision for End of Life Care, 2015.

22 National Council for Palliative Care. Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives, 2012.

**For community SPC services across London in 2013-14:**

- 17 of 26 services are providing seven-day visiting.
- Five services are unable to provide telephone advice to professionals out of hours (St Clare Hospice, Royal Free Hospital, Haringey Community Team, Diana Team Newham [paediatric palliative care] and North East London NHS Foundation Trust's Redbridge Specialist Palliative Care Team).
- Six services are unable to provide telephone advice to patients or their families out of hours (as above, with the addition of University Hospital Lewisham).
- However, five services demonstrate best practice by providing face-to-face visiting at all hours (Saint Francis Hospice; Central and North West London – Camden; Central and North West London – Islington ELiPSe; Guy's and St Thomas' NHS Foundation Trust; and St Christopher's Hospice).
- There is a large variation in service availability of community SPC between CCGs, with some CCGs providing 24/7 specialist care visiting and others providing only Monday to Friday, 9am–5pm services.
- Some variation of service availability exists within CCGs as a result of CCGs having more than one provider, with some CCG residents receiving significantly greater service than others.

Data on service availability over time has been analysed for both the LCA area (between 2012 and 2014) and the PallE8 area (between 2013 and 2014). This shows some improvement in SPC service availability in the LCA area, but some deterioration in service availability between the two years in the PallE8 area.

Since this service mapping exercise, the authors are aware of some further services which have been able to implement seven-day, face-to-face visiting. Despite this, the data reveals that SPC service availability across London is still below the minimum service level set by NICE in 2004.

Additionally, there are inequities in SPC service availability within many CCGs as a result of CCGs commissioning from more than one provider. Both hospital and community SPC teams across London require further support to achieve the service availability recommended. There may be opportunities to share resources across providers to achieve this and to learn from services which are achieving or exceeding the quality standard.

## **5.2 Recommendations for commissioners**

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- Both hospital and community SPC teams across London require further support to fully achieve the 2004 NICE quality standard for cancer.
- As a minimum, SPC services in hospital and community should be supported to provide face-to-face visiting from 9am–5pm, seven days a week, and telephone advice 24 hours a day, seven days a week.

# 6: Correlation of community Specialist Palliative Care and hospice services to CCG proxy need measures

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SPC should be provided according to need within populations of patients<sup>23</sup>. It is important to ascertain whether current SPC services are providing care to all of the patients who need it.

However, we do not have a total for this population as there is no nationally accepted measure of patient need. For the purposes of this service evaluation, two ways of approximating need have been explored to allow us to compare what might be needed with current provision.

## **6.1 Ratio of cancer patients seen to cancer deaths (expressed as a percentage)**

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For the purposes of this analysis, the numbers of cancer deaths in each CCG have been used as a proxy for SPC need, while recognising the limitations of the proxy.

If it is assumed that the same proportion of the patients who die of cancer, need the same level of SPC input in each CCG, the number of patients with cancer in a given CCG, who were seen by an SPC service, could be divided by the number of cancer deaths in that CCG, to give a proxy for need. This methodology suggests that there is considerable variability in the percentage of patients in need who receive the service between CCGs. This is illustrated in Appendix 6.

In reviewing this data, it is important to remember that:

- cancer death figures by CCG are a proxy measure and not a direct measurement of need
- cancer death figures used are from 2012 and this service review is for 2013-14
- not all patients seen will die within the same year
- this percentage may not reflect the service to need ratio for the population with non-malignant diseases
- patients living in the boundaries of the LCA and PallE8 defined areas may be accessing SPC services outside the area of measurement in this study which may result in the ratio in those CCGs being underestimated

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<sup>23</sup>National Council for Palliative Care. Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives, 2012.

- there are a number of patients who were not classified by CCG and this will impact on the accuracy of the data

A deprivation measure is also shown in Appendix 6 as this may be an additional influence on the need for SPC. This analysis was made for community SPC and hospice in-patient specialist SPC.

#### **For community SPC services across London in 2013-14**

- There is a large variation by CCGs across London in the ratio of patients who were seen by community SPC services to those who died with cancer. This is especially the case in North East London (NEL) and North Central London (NCL).
- NEL also has higher deprivation scores suggesting that the gap between patients seen and patient need may be even higher.
- There are a few areas with high levels of patients seen compared to patient deaths in NEL and NCL such as Islington CCG and Camden CCG which suggests good provision of services.
- Hammersmith and Fulham CCG appears to be an outlier in North West London with fewer cancer patients seen per 100 cancer patient deaths.

#### **For in-patient SPC services across London in 2013-14**

- There is a large variation in the ratio of patients who died with cancer to those who were seen by in-patient services, with Barking and Dagenham CCG having the lowest ratio and Central London (Westminster) CCG the highest.
- CCGs with higher deprivation scores do not generally have a higher ratio, with Barking and Dagenham CCG having the lowest ratio.

## **6.2 Ratio of patients seen by community SPC to patients seen in hospice in-patient SPC units**

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For each CCG, a ratio was derived for patients seen by community SPC to patients seen in SPC hospice in-patient units. This gives a picture of the relative provision of community and hospice in-patient SPC services in each area. The results can be seen in Appendix 7.

In reviewing this data, it is important to remember that:

- there is no standard available for the appropriate ratio of SPC community to SPC hospice in-patient visits
- in some areas, commissioning and service models will impact on the relative availability and therefore activity of SPC community and SPC hospice in-patient teams

#### **Across London in 2013-14**

- The data reveal a wide variation in the ratio between patients seen by community SPC to patients seen in hospice in-patient SPC units. This raises questions about equity of access to the different types of SPC across London CCGs.
- Hillingdon appears to be an outlier, with a significantly higher ratio of patients seen by community SPC to patients seen in hospice in-patient SPC units.
- The four lowest ratios are all in North East London with City and Hackney and Waltham Forest CCGs demonstrating the lowest.

There is currently no way of measuring whether SPC services are responding to the population in need of SPC. Proxy measures such as the ones devised here can suggest variations in meeting need but should be interpreted with caution. Further examination of the reasons for variations noted is required.

### 6.3 Staffing

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As part of reviewing provision of SPC services in London, providers submitted staff mix and staffing resource levels. We attempted to compare how SPC provision in each of the sectors across London in 2013/14 compares with the national recommendations for the minimum requirements of SPC provision outlined in the December 2012 publication, *Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives*, a guidance developed in partnership with the Association of Palliative Medicine, National Council for Palliative Care and Marie Curie<sup>24</sup>. This data has not been included as part of this report for a combination of reasons:

- Commissioners commission a service, rather than the personnel quotas to provide it.
- Methodological challenges in applying the guidance meant that conclusions would have been unreliable. These challenges included:
  - The difficulty of comparing different CCG clusters when different types of service are split variously between different providers.
  - Organisations which provide more than one type of service differ as to how they allocate to each service the time of staff whose work pattern crosses service boundaries.
  - Variations in staffing mix or levels may reflect providers' choice of service model. Current evidence does not allow us to be definitive about which models of service are associated with the most favourable outcomes.

However, difficulties in application of the guidance notwithstanding, it is worth commissioners noting that the data indicate a likelihood that staffing levels in all types of SPC provision frequently fall short of national guidance and that this is a probable contributor to the service shortfalls that have been identified.

### 6.4 Recommendations for commissioners

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- Commissioners should be aware of how their CCG performs against proxy measures for SPC need.
- Outlying SPC services should be supported to understand why they differ from other services.
- Commissioners should review staffing levels with their local SPC services to ensure they are in line with national recommendations.

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<sup>24</sup> APM, Cons Nurse in Pall Care Ref Gp, Marie Curie Cancer Care, NCPC and Pall Care Section of RSM, 2012.

# 7: SPC service activity by care setting for cancer versus non-cancer diagnosis

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## 7.1 Data analysis – cancer versus non-cancer patients

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The analysis identified SPC service activity (patient counts) by cancer and non-cancer diagnosis for London-wide SPC services within three settings – hospital advisory, in-patient beds and community palliative care – and they were compared to previous service mapping data collected in 2012 and 2013 (Appendix 8). This data demonstrates that London services vary to some degree in the proportion of non-cancer patients they see.

### Hospital advisory

- For a number of hospital advisory services, there are valid reasons for the cancer to non-cancer patient ratio observed being atypical.

For example, three hospital advisory services observed to have the highest percentage of cancer patients see limited non-cancer patients as they are primarily cancer centres.

- Discounting the above exceptions, 2014 data indicate that, of the patients seen by hospital advisory teams, the percentage with non-cancer diagnoses varied from 15% to 50%.
- 17 out of 23 (74%) services indicate they have increased non-malignant referrals from 2012 to 2014.
- 22 out of 28 (79%) services have a higher non-cancer patient rate compared to the national average for hospital advisory teams which is 25% <sup>25</sup>.

### In-patient units

- 2014 data indicate that, of the patients seen by in-patient units, the percentage with non-cancer diagnoses varied from 5% to 30%.
- Nine out of 16 (56%) adult services increased their proportion of non-malignant referrals from 2012 to 2014.
- 14 out of 16 units (88%) increased their non-malignant referral proportion of non-cancer patients to adult in-patient units to a level higher than the national average.

### Community palliative care

- 2014 data indicate that, of the patients seen by community palliative care teams, the percentage with non-cancer diagnoses varied from 10% to 35%.
- 16 out of 20 (80%) adult services which contributed relevant data increased their proportion of non-malignant referrals from 2012 to 2014.
- The Minimum Data Set data for 2014 showed that 17% of all referrals to community services nationally had a primary diagnosis which was not of malignancy. The study data indicates that 17 out of 23 (74%) adult SPC services in London accepted referrals for people with non-malignant illnesses.

In summary, this mapping exercise indicates that London SPC hospital advisory, community and hospice in-patient services, on average, see more non-cancer patients than national averages. In addition, the proportion of non-malignant referrals has increased on average from a similar 2012 mapping exercise.

However, given that non-cancer deaths accounted for 71% of all deaths in 2014, London still has a significant unmet need of non-cancer patients accessing SPC services.

## **7.2 Recommendations for commissioners**

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- It is recommended that CCGs from across London work with their local clinicians, patient groups, the voluntary sector, social care, public health organisations and local SPC services to understand need.

The CCGs can then develop, fund adequately and evaluate appropriate cost-effective SPC services. These services should meet the need for symptom control and psychosocial support of patients with advanced malignant or non-malignant diseases and their family/carer.

- When addressing local SPC needs, commissioners are asked to note that previous national guidance focused on the cancer patient population (NICE 2004), which often guided SPC service development at that time.

Recent relevant guidance (eg NICE EOLC *Quality Standards*, 2011; *One chance to get it right*, 2014) has highlighted that SPC should be fully accessible for all adult patients with relevant complex needs, irrespective of their diagnosis. Therefore, commissioners may need to review their local SPC service capacity to accommodate this likely increase in demand.

# 8: SPC service demographic characteristics

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## 8.1 Age breakdown

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In this study of London SPC services, we reviewed access to services across three age groups: under 65 years; between 65–84 years; and over 85 years; and in three settings – hospital advisory, community and hospice in-patient units in 2013/14 (Appendix 9).

The data illustrates that between:

- 40% and 90% of adult patients seen in a SPC hospital advisory service setting were over 65 years old; of which 6% to 8% were over 85 years old
- 60% and 80% of adult patients seen in a community SPC service setting were over 65 years old; of which 5% to 32% were over 85 years old
- between 60% and 80% of adult patients seen in a SPC hospice in-patient unit were over 65 years old; of which between 8% to 26% were over 85 years old

It is interesting to compare this data with the most recent national survey of patient activity data for SPC services which shows<sup>26</sup>:

- 29% of referrals involved patients aged 25–64 years (deaths in this age group account for 13% of all deaths excluding external causes)
- 54% involved patients aged 65–84 years (who account for 46% of deaths overall excluding external causes)
- 16% involved those aged 85 and over (who account for 39% of deaths excluding external causes)

The relatively low proportion of eldest elderly (85 + years) receiving SPC services nationally, when compared to the mortality rates for each of the age groups, may indicate a disparity in access for this age group. There is evidence that patients over 75 years had the highest preference to die in a hospice and the least chance to receive it<sup>27</sup>. The data from this study shows a similar picture for the London region.

This data illustrates that there is a disproportionately low representation of people over the age of 85 within London SPC settings compared to national mortality figures, but not when compared with national data for access to SPC services.

## 8.2 Ethnicity breakdown

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In terms of equity of access to services on the basis of BAME status, it is difficult to make robust conclusions given that the:

- BAME status for patients accessing SPC services has been recorded with variable level of quality
- ethnic breakdown of BAME patients accessing SPC services would not necessarily correlate with the overall ethnic breakdown of a CCG covering all age groups, given the average older age of SPC patients. Only 4.8% of the England population aged over 65 years old are from BAME groups compared to the overall 14.6% BAME groups represented across all age groups<sup>28</sup>

<sup>26</sup> Dixon J, King D, Matosevic T, Clark C, Knapp K. *Equity in the provision of palliative care in the UK: review of evidence*. Personal Social Services Research Unit, London School of Economics and Political Science, London, 2015.

<sup>27</sup> Gomes B, Calanzani N, Higginson IJ. *Local preferences and place of death in regions within England 2010*, Cicely Saunders International, London, 2011.

<sup>28</sup> Office of National Statistics. ONS census ethnicity by age, 2011.



It can be assumed that the need for SPC in these groups will increase over time as the BAME populations age. As such, it is imperative that SPC services are tailored to meet their needs.

A multivariate analysis on the recent VOICES bereavement survey<sup>29</sup> illustrates that, in terms of care experience, the respondents representing the decedents from BAME groups in this study felt they were less likely to receive help to allow their relative to stay at home during the final stages of their illness (at 95% rather than 99% significance level).

### **8.3 Recommendations for commissioners**

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- Given the generally ageing population and the likely increase over time in percentage of people over the age of 65 from a Black, Asian and minority ethnic (BAME) background, it is recommended that CCGs look at their demographic projections and work accordingly with their local clinicians, community groups and SPC services to develop, fund and evaluate appropriate, cost-effective services.

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<sup>29</sup> Dixon J, King D, Matosevic T, Clark M, Knapp M. Equity in the *Provision of Palliative Care in the UK: Review of Evidence*, Marie Curie, 2015.

# 9: Conclusions

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There is evidence of improvement since 2012 of SPC service access by non-cancer patients across London and in some out-of-hours service provision in West and South London (ie London Cancer Alliance areas). **However, SPC out-of-hours service availability across London still falls short of national guidance and accepted best practice.**

This report is limited by the lack of nationally accepted measures of SPC patient need, outcome or service quality to act as benchmarks. An analysis of provision of SPC against two proxies for need has been presented in the report but should be reviewed with caution. It was not possible to report on some of the information collected, including BAME populations, as a result of data quality issues.

The report makes a series of recommendations for commissioners on how they can implement the findings from this report to improve end of life care for residents in their area. However, without clear quality and outcome data, it is hard for commissioners to determine the best ways to use limited resources. **Nevertheless, to ensure 24/7 access to SPC telephone support and 9am to 5pm 7/7 access to face-to-face visiting, in line with national guidance, must be a priority.**

The anticipated launch of a national individual-level dataset in 2017 of SPC services including demographic details, activity information and patient outcomes data will be an important milestone towards providing evidence on outcomes, and (in the longer term) facilitating genuine equity of access across London.

LCA, PallE8 and Marie Curie believe everyone living with a life-limiting illness should have access to high quality care and support, which meets all of their needs.

Given that demands on existing stretched resources are only set to grow, we must tackle these issues and find solutions to avoid failing vulnerable people across London at the time they need us most. Monitoring the changing provision of SPC services across London is an important step along the road to improving care.

**This report has been jointly produced by the London Cancer Alliance, PallE8 and Marie Curie in collaboration with Specialist Palliative Care providers across London.**

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Charity reg no. 207994 (England & Wales), SC038731 (Scotland) A267a

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A joint report by

LONDON  
CANCER  
ALLIANCE **LCA**

**PallE8**  
● ● ●



Care and support  
through terminal illness | **Marie  
Curie** 

23 October 2015

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Title of consultation

End Of Life Care In London

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Organisation

London Assembly Health Committee

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## Introduction

The London Fire and Emergency Planning Authority (LFEPA) runs the London Fire Brigade (LFB). The 17 members of the Fire Authority are appointed by the Mayor of London. Eight are nominated from the London Assembly, seven are nominated from the London boroughs and two are Mayoral appointees. LFB is the busiest fire and rescue service in the country and one of the largest firefighting and rescue organisations in the world. We are here to make London a safer city and our vision is to be a world class fire and rescue service for London, Londoners and visitors. We will always respond to fires and other emergencies, but our work has changed over the years with a much stronger emphasis now on fire prevention and community safety.

## Response

The LFB welcome the opportunity to contribute to the London Assembly Health Committee's investigation into end of life care in London and note that focus will be given to the challenges faced by older people living alone and coming to the end of life. This is of particular interest to the LFB due to the prevalence of such individuals in the occurrence of fatal fires and those where injuries were serious enough to require lengthy hospitalisation.

Our published evidence<sup>1</sup> shows that people with care and support needs arising from physical, mental and cognitive health issues are significantly more at risk from fire due to an impaired ability to recognise fire risk, and respond appropriately or escape if a fire happens. Where a person is receiving end of life care at home, these risks could be identified through a routine fire risk assessment carried out as part of a Home Fire Safety Visit where advice on reducing fire risk would be given, tailored to the individuals fire risk profile. In addition to our standard advice to fit smoke detection on each level of the home in all areas of risk, where a person has limited ability to respond if a fire happens, we would also recommend that the smoke detection be linked to a monitored community care alarm which would raise the alarm even when the person is unable to do so themselves and before the fire had fully developed. Similarly, where a person's ability to escape is impaired, we would recommend the installation of automatic fire suppression systems such as sprinklers and water mist systems which have the potential to prevent death and injury.

As such, we would ask that the Health Committee's investigation includes considering how to raise awareness of the need to include fire risk assessment as part of the individual care planning process which forms part of the five new Priorities For Care set out by the Care Quality Commission, so that contacting the LFB to arrange a joint Home Fire Safety Visit becomes the norm in these circumstances.

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<sup>1</sup> Reports:

[FEP2484 Review of Accidental Dwelling Fires and Fatalities 2014-15](#)

[FEP1952 Fire Safety of People in receipt of Domiciliary Care](#)

30 October 2015

Response to London Assembly briefing paper on End of Life Care (EOLC) in London from: Dr L Caroline Stirling, Clinical Director, EOLC Clinical Network NHS England (London); Dr Jonathan Koffman, Senior Lecturer in Palliative Care, Cicely Saunders Institute, King's College London; Meeta Kathoria, Head of Programmes, Marie Curie; Claire Henry MBE, CEO, National Council for Palliative Care and Dying Matters; and Brian Andrews, Chair, Pan-London EOLC Alliance Lay Representative Board.

## London Demographics

Of the 8,000,000 people in London, about 75% (6,000,000) are adults, and 60% are white (2011 census).

53% = 18-65 (3,250,000), 13% = 65-84 (476,000 aged 65-74, 310,000 aged 75-84), 2% = 85+ (124,000)

In 2014, there were ~47,000 total deaths, 28% of those from cancer.

91% deaths are in 65+, 75% deaths are in 75+  
33% deaths are in 85+

NB: Only ~15% of patients seen by specialist palliative care (SPC) are 85 years or older.

“Facing the transition to life’s end is an emotionally vulnerable time for us as patients and for those of us who love them. We want professionals to recognise this is often a traumatic period in our lives and a memory of a good death can support us as carers to feel consoled after they have died, whereas the memory of a death involving unnecessary suffering can often be a long term painful memory.”

-- Launch statement from lay representatives  
of the Pan-London EOLC Alliance

## Overview of end of life care

*What do we mean by “end of life care” and how is it different from palliative care?*

Death is a certainty and we all require excellent compassionate care at the end of our lives.

End of life care (EOLC) refers to the last months or years of life –as well as days of life. Palliative care is both a specialty and approach to provide support, expertise and advice for people with physical / non-physical burden – and those important to them – at any stage of a life threatening illness, including at the end of life.

## *What does good end of life care look like, from a patient perspective?*

What matters most to patients in end of life care is<sup>1</sup>:

- Good pain and symptom control
- Family support and reduction in burden on family
- Having priorities and preferences listened to and accorded with
- Achieving and sense of resolution and peace (time and support for preparation)
- Well-coordinated and well-integrated care with continuity of professionals.

“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people that are important to me, including my carer(s).”

-- *Every moment counts*, National Voices (2015)

This requires:

- Compassionate resilient health and social care staff who have the skills to provide quality EOLC
- Access to available community nursing (24/7) and specialist palliative care staff (7/7), and adequate basic care provision in place of choice (ie carers, housing, companionship, etc)
- Ability to share information about EOLC wishes between care settings (ie hospital and community, etc)
- Prioritisation and focus on EOLC by Health and Wellbeing Boards (HWBs), clinical commissioning groups (CCGs) and providers
- Society’s acknowledgement of the reality of EOLC

The National Palliative and End of Life Care Partnership has documented six ambitions to bring about vision of good end of life care<sup>2</sup>:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

There are eight foundations on which these ambitions are built:

1. Personalised care planning
2. Shared records
3. Evidence and information
4. Involving, supporting and caring for those important to the dying person

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<sup>1</sup> Cicely Saunders Institute, Department of Palliative Care, Policy & Rehabilitation, King’s College London | [link](#)

<sup>2</sup> Ambitions for palliative and end of life care: A national framework for local action 2015-2020, National Palliative and End of Live Care Partnership (2015) | [link](#)

5. Education and training
6. 24/7 access
7. Co-design
8. Leadership

## Addressing EOLC in London

There are significant variances in the cost of EOLC across London as well as how the health and care system is addressing it.

### Spend per death / CCG

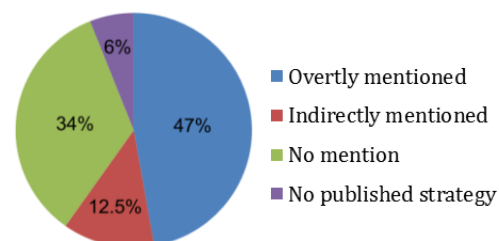
For London CCGs, there is a significant variation in spend on palliative care per death across ranging from £540 to £3,710 per death.<sup>3</sup>



### Health and Wellbeing Boards

There was variance across 32 London Health and Wellbeing Boards in addressing EOLC within their 2014 strategies:

- 47% (15/32) – Overtly mention EOLC
- 12.5% (4/32) – Indirectly mention EOLC
- 34% (11/32) – Do not mention EOLC
- 6% (2/32) – Have no published strategy



### Acute hospitals

For the 16 London hospitals submitting data to the 2014 RCP National care of the dying audit, we find:

- 25% had educational programme for generic clinicians (4/16)
- 13% had board representation and planning for EOLC (2/16)
- 50% had process to get formal feedback for bereaved relatives (8/16)

### 7-day SPC availability

The London Cancer Alliance/PallE8 and Marie Curie review of specialist palliative care (SPC)<sup>4</sup> found:

- 70% of hospital advisory SPC adult services and 35% of community SPC adult services were NOT able to provide seven-days-a-week visiting.
- 13% of hospital advisory SPC adult services and 19% of community SPC adult services were NOT able to provide telephone advice between 17:00 and 09:00.

<sup>3</sup> Data from Channel 5 FOI request for budget year 2014/15 (June 2015)

<sup>4</sup> **A review of specialist palliative care provision and access across London**, London Cancer Alliance, PallE8 and Marie Curie (2015) | [link](#)

## **Diversity and provision of SPC**

It is difficult to make robust conclusions regarding the equity of access of specialist palliative care to black and minority ethnic (BAME) patients as the quality of recording SPC access data may vary. Additionally the ethnic breakdown of BAME patients accessing SPC services may not necessarily correlate with the overall ethnic breakdown of a CCG across all age groups, given the older age of SPC patients. (Only 4.8% of the England population aged over 65 years is from BAME groups, as compared to the overall 14.6% BAME groups represented across all age groups.)

Nonetheless, as the populations in BME groups increase in age so, too, will the need for SPC for these groups. It is therefore imperative that SPC services are tailored to meeting their needs.

A multivariate analysis on a recent VOICES bereavement survey found that, in terms of care experience, respondents representing the decedents from BAME groups felt that they were less likely to receive help to allow their relative to stay at home during the final stages of their illness. This reiterates the need for tailored SPC services for BAME patients.

## **Provision of SPC to patients with non-cancer**

Seventy per cent of patients who die have a non-cancer diagnosis (rather than a cancer diagnosis), and the symptom burden – and therefore palliative care need – in non-cancer patients is high.

Yet the majority of patients seen by SPC teams in London have a cancer (rather than non-cancer) diagnosis. Between 2012 and 2014 this trend was decreasing by most services, and there is significant variation between services. Whilst 50-80 per cent of patients seen in hospital and community services have a cancer diagnosis, 70-80 per cent of patients admitted to hospices have cancer.

## **Patients who need palliative care and are seen by SPC teams**

Murtagh et al (2014) estimate that based on updated ICD-10 causes of death, underlying/contributory causes, and hospital use, at least 63 per cent of all deaths could benefit from palliative care (lower and upper mid-range estimates are 69.10% and 81.87%, respectively).

There is currently no way of measuring whether SPC services are responding to those in need of SPC. Proxy measures such as the percentage of patients who died of cancer suggest variations in meeting need, but should be interpreted with caution. Using this as a proxy measure, there is a significant variation within London, in which 17-45% of those in need are seen. Commissioners should be aware of how their CCG performs against proxy measures for SPC need.



## EOLC perceptions: Variances between London and England

ComRes interviewed 2,016 British adults online to determine perceptions about death and end of life care Error! Bookmark not defined.

	London (%)	NATIONAL (GB) (%)
Whether believe more acceptable to talk about dying now than 10 years ago	57	64
Think about dying and death at least once a week	36	32
Whether think people in Britain are uncomfortable discussing dying	71	72
Say they have written a Will	29	35
Say they have registered as an organ donor/have a donor card	24	32
Say they have taken out life insurance	29	31
Spoken to someone about their funeral wishes	24	27
Asked a family member about their end of life wishes	24	18
Say they have written down wishes about care if couldn't make decisions themselves	7	7
Agree if people became more comfortable discussing dying easier to have end of life wishes met	71	71
Agree quality of life more important than how long they live for	69	79
Providing end of life care should be a fundamental part of the work of the NHS	68	75

## EOLC: The national picture

### How London EOLC compares with the national picture

Data from ONS<sup>5</sup> and the Health and Social Care Information Centre<sup>6</sup> found that in London:

- 26% of bereaved relatives surveyed rated the **care they received from GPs** as excellent, as compared with the national average of 35%.
- 34% of bereaved relatives rated the **care they received from district and community nurses** as excellent, as compared with the national average of 45%.
- 66% of carers felt they were **included or consulted in decisions**, as compared to the national average of 73%.

### EOLC: Getting the attention in the health sector?

Whilst EOLC is gaining attention, there is more that must be done. Channels such as CQC inspections, GMC guidance, ambitions for palliative and EOLC within the Francis Report, Ombudsman, and Neuberger, health select committee report and other publications have provided a focus.

However, focus is inadequate. This may be due to a number of reasons:

- **Lack of focus or prioritization by CCGs/ HWBs** – The call for wide scale transformation and great scale of financial pressures for the Department of Health and the NHS in England over the next five years may reduce the opportunity for improving EOLC, as commissioners may find competing priorities to meet the wider population agenda.
- **Discomfort related to EOLC**
  - Sense of ‘failure’ by health professionals / organisations / society that approaches to treatment are fallible/inadequate, and that death occurs for everyone. Doctors, nurses and social care professionals are trained and focused on treating disease and avoiding death, and death is still often a taboo subject.
  - Lack of confidence /fear of approaching this topic with patients and those important to them.
- **Poor and inequitable funding** for EOLC in some areas by commissioners / providers (as noted above)
- **Fragmentation in the systems** that commission and provide end of life care, (ie NHS, local authorities and the voluntary sector)
- **Lack of system leadership** to drive improvement in person centred EOLC.
- **Difficulty identifying tangible quality outcomes** for EOLC (eg quantifying a ‘good death’ against more tangible x/y successful hip operations). The anticipated launch of a national individual level dataset in 2017 of SPC services including demographic details, activity information and patient outcomes will be an important milestone towards providing evidence on outcomes, and (in the longer term) facilitating genuine equity of access across London.

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<sup>5</sup> ONS Survey of Bereaved People VOICES (2011/12)

<sup>6</sup> Health and Social Care Information Centre Carers survey (2012)

## New clinical guidelines from NICE versus the Liverpool Care Pathway

The new clinical guidelines from NICE have exposed the training need for non-specialist staff, and the need for systematic assessment of the quality of care in the last days of life.

They require both individuals and organisations to develop systems / processes / training to ensure they are able to guarantee compassionate high quality individualized care for patients and those important to them, and to measure this quality.

## Existing social care guidance to adequately address the requirements for good EOLC

The Social Care Institute has some resources ([www.scie.org.uk/adults/endoflifecare](http://www.scie.org.uk/adults/endoflifecare)) which adequately address the requirement for good EOLC. However the level of compliance against guidance is unknown.

As local authorities are responsible for public health, they will also need to get the public to talk about death, dying and bereavement and to encourage the public to put their affairs in order and get on with living.

## EOLC: The London perspective

### London best practice

To understand where EOLC is particularly good in London, we must first determine how and where 'best' is assessed. Whilst data finds areas that are the best in the country, there are also areas in which EOLC survey data finds it to be rated worst in the country.

**Bereaved relatives survey** (VOICES – 2011-12) – When asked, *Overall, taking all care into account, how would you rate his/her care in the last three months of life?* those respondents responding with 'outstanding' or 'excellent' found Islington (56%) and Central London (Westminster) (50%) to be rated the best in the country! However, Newham (26%), Waltham Forest (28%), also in London, are rated lowest in the country. **NB:** *ONS advises caution in using CCG level data, as the sample sizes are small and thus might not be statistically significant.*

**Location of death** – The bereaved relatives' survey correlates somewhat with data on the location of death, as per the table below.

Location of death data for 2014, Q1-4:

Location	Preference (n=1351)	Actual - National		Actual - London	
		2011 (436,573)	2014 (470,541)	2011 (45,556)	2014 (47,586)
Hospital	3%	50.2%	47.2%	56.7%	54.0% (46.3 – 68.3%)
Home	63%	21.7%	22.4%	20.5%	22%
Care home	3%	20.6%	23.2%	14.4%	15.8%
Hospice	29%	6.0%	5.8%	6.7%	6.8%
DIUPR*	N/A	42.3%	45.6%	35.0%	37.8% (27.3 – 55.5%)

\*DIUPR = death in usual place of residence

NB:

Highest % hospital deaths = Newham and Waltham Forest

Lowest % hospital deaths = West and central London

## Provision of SPC

### Community SPC service provision

Best examples: In 2014<sup>4</sup> community SPC services serving the majority of residents in Barking and Dagenham, Havering, Islington, Croydon, Kingston, Richmond, Greenwich and Southwark provided access to face to face visits from community SPC services 24/7.

Areas with poorest provision: In 2014 community SPC services serving the majority of residents within Haringey, Redbridge, Waltham Forest, Harrow and Hillingdon did not provide any access to face to face visits at all either at weekends or on bank holidays. In addition, community SPC services supporting patients in Haringey and Redbridge did not provide any telephone advice services OOHs either in weekday evenings, weekends or bank holidays. North Brent has the poorest level of provision.

### Hospital SPC service provision

Hospital services cannot be drilled down into boroughs, as this was not included in the report. However we can look at teams providing high and low levels of service.

Best examples: Hospital SPC teams who go above and beyond NICE guidance and have a 7 day 24/7 visiting capacity are: Central & North West London Trust, University College London Hospital, Guy's and St Thomas' Hospital, King's College Hospital, University Hospital Lewisham and the Royal Marsden.

Areas with poorest provision: Teams who have the minimum SPC services/only a telephone advice service, and one which is limited are: Princess Alexandra, Whittington, North Middlesex & Barnet & Chase Farm.

### What makes 'good' boroughs good?

- Focus on EOLC by CCG /HWB with needs assessment and strategy involving health and social care
- Higher investment overall
- 24/7 available palliative care and community nursing care
- Access to hospice beds
- Focus on EOLC by, and education of generic clinicians in primary care (GPs, nursing homes staff) and community care

## Understanding why worse EOLC exists for specific population segments

Understanding why particular groups of people, such as the oldest old, or people from BAME backgrounds, tend to receive worse end of life care and how this is measured is vital to improving it.

### *The oldest old*

The oldest old are a rapidly growing demographic group in the UK, yet their health and social care needs are seldom considered, particularly at the end of life.

Recent research from the CSI at King's College, for example (Gao et al 2014) observed that across the period 1984-2010 home deaths became less likely with increasing age. Sleeman (et al 2015) observed that deaths in hospices remained more likely for younger than older groups (average age 70 years old).

Older people with advanced cancer are less likely to receive analgesia (Higginson & Wei 2012); data from the General Practice Research Database (GPRD) who died in 2000 - 2008 revealed that patients > 60 had significantly lower chances of receiving opioids than those < 50 years. This remained so after adjusting for co-morbidity.

### *BAME communities*

London is the most ethnically diverse region of the UK with the lowest proportion (59.8%) of people who identify as being white British.

Analysis of mortality data for 93,375 cancer deaths of ≥65 years in London from 2001-2010 examined location of death in relation to the decedent's country of birth (Koffman et al 2014): hospice deaths were *less likely* for those born in Asia, Africa and 'other' geographical regions. Home deaths were *less likely* for those born in the Caribbean. The last preferred location of death – hospital was *more likely* to occur among those born in Asia and Africa.

Possible reasons for these disparities in service use include (i) lack of awareness and knowledge of palliative care and related services (ii) referral patterns to specialist palliative care; (iii) lack of understanding amongst professionals about exactly which patients to refer and gate-keeping by services; (v) complex linguistic and communication barriers; (vi) preferences including for more aggressive or curative care at the end-of-life, or a cultural mistrust of end-of-life care and (vii) strong religious and familial support systems.

There are, however, a number of weaknesses from this body of research. Firstly, our reliance on country of birth as a proxy for ethnicity is open to lots criticism. Ethnicity is not recorded on death registration data so our research is limited to first generation migrants. We are very worried that the poor quality or absence of recording of ethnicity data at this critical time will lead to 'social invisibility' of paradoxically growing populations

### *Understanding why so many Londoners die in hospital rather than at home*

There are several reasons for this, including:

- Likely inadequate resourcing and access to health and social community services to avoid admission to hospital and facilitate timely discharge of patients from hospital to home
- The systems and process changes required to successfully implement and realize the benefits of EPaCCS – CMC is either not prioritized or invested in effectively, etc
- Community nursing and SPC staff are not available 24/7 in all boroughs
- Poorly trained generic staff in all settings
- Likely poor uptake of palliative care by BAME and elderly

### **Resourcing EOLC in London**

There is a huge variation in spend on SPC and EOLC by borough – up to 30 times – and the dependence on unpaid carers and voluntary organisations is great.

There were 600,000 more unpaid carers in the UK in 2013 than there were in 2001, and with an increasing ageing population, there are more people than ever in need of care and support. With social care budgets being cut, the burden falls more on relatives and friends to provide essential services; burnout is a common problem.

We know that informal care is a significant part of the costs of care for people in advanced illness or at the end of life. McCrone (2009) showed that informal care costs are often considerably higher than formal care costs. Gardiner et al. (2013), in a systematic review of the literature on the financial impact of caring for family members receiving palliative and end of life care, identify 17 relevant studies that variously report direct and indirect financial costs associated with caregiving and multidimensional caregiver burden (such as delaying studies or medical treatment).

### **Diagnosis**

The quality of EOLC does depend on diagnosis. For example, there are data showing that patients with non-cancer receive less palliative care than those with cancer<sup>4</sup>. Palliative care has traditionally been focused on people with cancer, and whilst it is recognised that this needs to shift, there is still a long way to go.

### **Patients with multiple conditions**

There are additional challenges to good end of life care that arise when a person is suffering from multiple conditions, such as cancer with dementia. These include:

- Predicting when death will occur
- Ensuring wishes are established before capacity is lost
- Providing care for the very old who may be living alone or in a care home

## Older people who live alone

Specific challenges faced by older people who live alone include:

- Practical – shopping, cleaning, cooking, self-managing their (often multiple) long term conditions and related medical appointments, financial pressures
- Emotional – social contact, loneliness, physical frailty leading to a sense of vulnerability and a sense of being a burden on society
- Physical burden of LTCs – frailty, mobility, memory.

## Social assumptions about oldest old people

There is the potential for age discrimination in how the needs of the oldest old might be treated differently in comparison to similar the health and care needs of younger people. It has also been suggested by some older people are more accepting of their distress. There is certainly evidence they are less likely to complain –they are not a vocal constituency.

## EOLC for an ageing London population

London is not equipped is London to deal with an increasingly aged population, in terms of end of life care:

- Housing – inadequate
- Informal carers of the very old – inadequate
- Staff – The bell curve of age for professionals skilled in EOLC bulges at ~50 years, meaning that there will be a paucity of professionals skilled in EOLC and SPC in the next 10 years.

## Social isolation, EOLC and older people

To ensure good EOLC, health, social care and society each have a role to play.

### Social care / society

- Housing / care homes / supported living for elderly
- Practical support with ADL – carers, finance / benefits to ensure people can live independently
- Skilled social care staff who are able to care and communicate sensitively and confidently about EOLC.
- Support for carers pre and post death – information, recognition, single point of contact, bereavement support (pre and post death)
- Awareness and care for those of all cultures in terms of EOLC
- Increased discussions amongst public about dying (eg Dying Matters week)

### Health

- Skilled generic clinical staff in all settings – primary (including nursing and care homes) & secondary care – to facilitate identification of patients who are in the last year of life, to initiate a sensitive conversation to establish desire for information / discussion, and thereafter to provide information about the future, establish preferences and priorities for place of care & death, extent of treatment, and support for those important to the

patient. NB: For some patients, with diagnoses that affect capacity – dementia, parkinsons disease etc, such discussions need to occur much earlier in the disease process, to enable to patient to be able to participate in the discussions.

- Available generic staff 24/ 7 – ie community nursing staff – who have a presence in all settings including care/ nursing homes
- Available specialist palliative care staff 24/7
- Sharing of information related to preferences / decisions made about EOLC – EPaCCS, interoperability, NHS 111 etc
- Unified documentation that is transferrable and valid when a patient moves between settings – DNACPR / TEP decisions etc.

### Examples of exemplar public health approaches

#### *Hackney*

- St. Joseph's Hospice have 70 active, trained 'Compassionate Neighbours' from the three boroughs served by St. Joseph's – Age UK
- Funded jointly by the Cabinet Office and the local CCG.
- A network of trained volunteers who are willing to offer their time, companionship and support to people living in their community.
- St. Joseph's are planning to give them regular opportunities to meet and build relationships with each other.

#### *Weston*

- Weston Hospicecare is bringing together local agencies, schools and businesses for regular meetings
- They are working together to develop compassionate policies that can be implemented in schools, workplaces, businesses

NPCPC is testing out a compassionate employers programme care homes acute trust and hospices.

### London housing plans relevant to EOLC needs of the population

- Lewisham, Notting Hill Housing's Conrad Court: 78 apartment extra care scheme at Marine Wharf, Surrey Quays
- East Thames Housing Association are piloting innovative technology that better supports people with a diverse range of needs including older people, people with learning disabilities, those with mental health needs, and young people.
- Barnet Homes - planning application for a 51 unit dementia-friendly extra-care scheme on the site of Moreton Close sheltered block was approved
- Brent, a report by the council outlines their 'New Accommodation for Independent Living' (NAIL) to develop more local Extra Care and supported living accommodation. The NAIL project is set up to deliver a further 340 units of accommodation by 2017-18.
- Greenwich, the council are building 22 single-storey houses for people over 60 which are due to be completed later this year. The Bell Phillips designed scheme was a 2014 HAPPY winner and we look forward to following these.



- Barking & Dagenham – scheme planned that aims to encourage 'downsizing' from under-occupied family homes. More at: [www.ribaj.com/buildings/barking-courtyard-pensioners-downsize](http://www.ribaj.com/buildings/barking-courtyard-pensioners-downsize)
- Croydon - five providers under a 'provider alliance' including the voluntary sector, have been selected to lead the delivery of a £10bn, 10 year contract to improve older peoples' care.
- Age-friendly London - a housing for older people plan (we estimate shortfall of c10,000 units of specialist accommodation across the capitol), and
- £40m Mayor's Care and Support Specialised Housing Fund (funded by the DH) Phase2 bids are to be announced shortly

### Further action

To ensure that more people have access to high quality end of life care, we recommend:

- Increase focus on EOLC of HWB and CCGs, including an education strategy
- Mandate training in EOLC of all social and health care staff in all settings
- Call for equitable access in all boroughs to community nursing and SPC
- Highlight need to shift resources from acute to community providers to manage care out of hospital
- Assess and respond to need for housing and support for the increasing numbers of elderly in the next 15 years
- Provide incentives to employers to allow and support volunteering in, and to raise awareness of EOLC

### The Mayor's help

We request that the Mayor encourage and inspire changes as far as possible in the above. Additionally, we request the Mayor to adopt city-wide tactics proposed within the Compassionate City Charter.



## **Response to London Assembly Health Committee Investigation into End of Life Care in London**

### **Introduction**

- i. Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. A third of people with the disease die within a year of diagnosis, and more than half within two years. There is no cure.
- ii. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.
- iii. The devastating nature of MND means that palliative care is beneficial from diagnosis through to the end of life. We welcome the Health Committee's investigation into end of life care, and the opportunity to submit evidence on the experience of people with MND and their carers in London.

### **Our work on end of life care**

- i. In recent years the MND Association has undertaken two significant pieces of research into what people living with MND think and feel about end of life issues.
- ii. In 2012 we published *Choice and control when you have a life-shortening illness*, a report compiled by the Picker Institute Europe, which examined the views of 34 people living with MND on end of life issues.<sup>1</sup>
- iii. In 2013 we conducted the largest ever survey of people with MND in the UK on a range of issues, including end of life care. The *Improving MND Care* survey

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<sup>1</sup> Available at [www.mndassociation.org/Resources/MNDA/Life%20with%20MND/Documents/Choices%20and%20control%20FINAL.pdf](http://www.mndassociation.org/Resources/MNDA/Life%20with%20MND/Documents/Choices%20and%20control%20FINAL.pdf)

collected the experiences and views of more than 950 responses from people living with the disease in England, Wales and Northern Ireland.<sup>2</sup>

- iv. One of the findings was that people with MND wanted more information on the types of care and support available to them, and on the choices they could make, towards the end of life. In 2014 we responded to this by publishing the first comprehensive information guide on end of life issues for people with MND, which was subsequently named Patient Information of the Year 2015, by the British Medical Association<sup>3</sup>. We also use the insights gained from our research to campaign to improve end of life care services across England, Wales and Northern Ireland. The findings inform our response to this investigation.

### **Service provision in London**

- i. It has been recognised for several years now that palliative care is highly beneficial to people with neurological conditions such as MND from the point of diagnosis through to the end of life.<sup>4 5</sup> It helps the person manage their condition and symptoms, and to maintain the best possible quality of life. If changes in the person's condition and rate of progression are recognised in timely manner, these can act as triggers for the introduction of palliative care services. In our experience, from a service provision perspective, this is most likely to happen when there is holistic assessment and regular review from a multidisciplinary team (MDT).
- ii. Data are not routinely collected on access to palliative and end of life care services by people living with MND, or people with neurological conditions more generally. This makes it difficult to provide the committee with a complete picture of provision, and gaps in provision, in London.
- iii. Anecdotally, we know that the experience of people with MND is variable. Some receive a gold standard level of care throughout their journey with MND, with palliative care available from the outset, a range of services provided as the disease progresses and high quality care provided at the end. Others have limited contact with palliative care teams and services, either because appropriate services aren't commissioned or people aren't made aware of them. Perhaps most commonly, a person will receive a mixture of very good care, support, advice or information in one setting or from one service, and then will go stretches of time with no contact with palliative care services. They may also experience an episode of extremely poor care, for example a traumatic stay on a general hospital ward. Like many aspects of MND care, the reports we receive suggest that access to palliative and end of life care is a postcode lottery.

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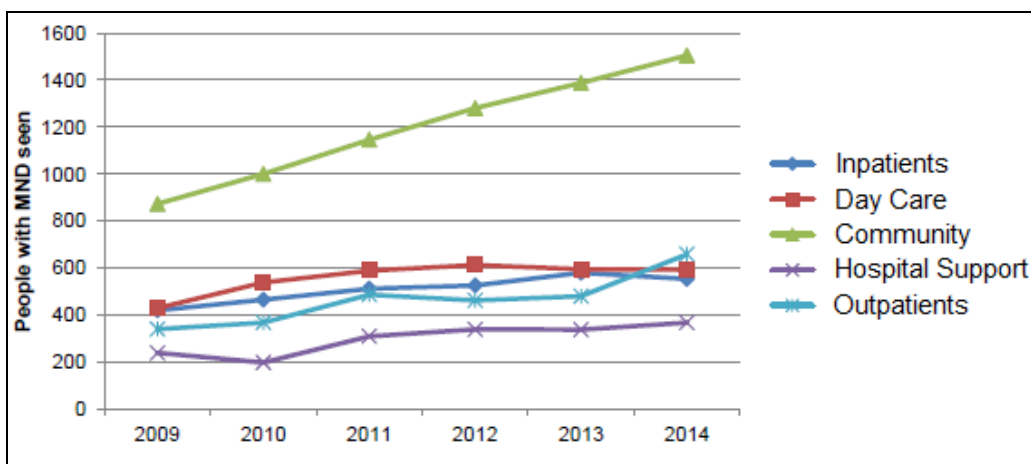
<sup>2</sup> Available at [www.mndassociation.org/Resources/MNDA/Campaigns/Documents/improving-mnd-care-report.pdf](http://www.mndassociation.org/Resources/MNDA/Campaigns/Documents/improving-mnd-care-report.pdf)

<sup>3</sup> Available at [www.mndassociation.org/life-with-mnd/Publications-pabmnd/end-of-life-guide](http://www.mndassociation.org/life-with-mnd/Publications-pabmnd/end-of-life-guide)

<sup>4</sup> *End of Life Care Strategy: promoting high quality care for adults at the end of their life* (2008) Department of Health

<sup>5</sup> National Council for [www.ncpc.org.uk/neurological-conditions](http://www.ncpc.org.uk/neurological-conditions)

- iv. A key way of improving access to palliative care services is for palliative care professionals to make referrals to and attend MDT meetings where the care of people living with MND is discussed by a range of professionals. In some boroughs, we have seen attendance at MDT meetings by palliative care professionals drop, which in turn impacts on quality of care. It is difficult to pinpoint the cause of the lower attendance. One reason may be because MND represents a relatively low number of people as a proportion of professionals' caseloads, and this can mean attending the meetings is viewed as less of a priority in the face of other pressures. Another reason is that pressure in 'the system' generally seems to have increased dramatically in the last few months, which is having a knock-on effect on many areas of care.
- v. Another problem we encounter is that people with MND are sometimes not considered palliative until their condition has deteriorated quite significantly. This means they are unable to access to some of the support that comes with palliative care, such as day therapy, respite services, clinical nurse specialist and consultant input, symptom control, home visits, complementary therapy and, where it exists, 24/7 advice and support, until a late stage.
- vi. The Government's review of choice in end of life care highlights the importance of a person being able to choose where they receive this care.<sup>6</sup> The model of the cost of end of life care produced by this review includes the cost of home adaptations. It is vitally important that people have access to sufficient and timely support for adaptations, if they are to be allowed a realistic choice about where they receive their care. It is particularly important that this support is available as soon as possible for someone with MND, and that it takes into account the person's future needs as their condition is likely to progress rapidly. Housing adaptations are problematic across the capital, with long waiting times (sometimes up to a year) commonplace.
- vii. Nationally, we know that people with MND's contact with specialist palliative care (SPC) services is improving. The National Council for Palliative Care (NCPC) collect data on SPC services and specifically about people with MND's usage of it. The graph below shows that more people with MND are receiving support from SPC, particularly in the community.



<sup>6</sup> The Choice in End of Life Care Programme Board *What's important to me: a review of choice in end of life care* (2015) <http://bit.ly/1CgZzGU>

Source: NCPC report produced for MND Association December 2014.

- viii. However a report on specialist palliative care services across London published in September 2015 found that in many boroughs community SPC services are not available at weekends and on bank holidays. This means that people who require specialist support, like people with MND, can only access it if they need it during working hours.<sup>7</sup> People's quality of life and death should not vary according to where they happen to live, or what time of day or night they have a need.

### **Inequity by diagnosis**

- i. The committee has rightly noted that that the palliative care support people receive largely depends on what condition they have, and that people with conditions other than cancer experience poorer access.
- ii. The palliative care movement has its roots in the care of people with cancer. However, the challenges involved in providing end of life care to people with neurological diseases can be quite different to those relating cancer (see Box 1).

**Box 1 - The challenges involve in the end of life care of people with neurological diseases:**

- Long duration of disease (in some cases)
- Sudden death
- Lack of predictable course, or fluctuating course
- Complex multidisciplinary care
- Specialist treatments
- Neuro-psychiatric problems (eg, behavioural and cognitive changes)
- Rapidly advancing diseases may need palliative care early on
- Many people die with but not from their neurological condition
- Variability of neurological conditions

Source: *End of life care in long term neurological conditions: a framework for implementation* (2011) NHS National End of Life Care Programme, Neurological Alliance, National Council for Palliative Care.

- i. The aforementioned review of SPC in London found that, in keeping with the national picture, SPC services see a disproportionate number of people with cancer than people with diseases other than cancer. Although this is slowly

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<sup>7</sup> *A review of Specialist Palliative Care provision and access across London – Mapping the capital.* Marie Curie, the London Cancer Alliance and PalleE8  
[www.mariecurie.org.uk/globalassets/media/documents/research/london-spc-provision-report.pdf](http://www.mariecurie.org.uk/globalassets/media/documents/research/london-spc-provision-report.pdf)

improving, the report concluded that 'London still has an unmet need concerning non-cancer patients accessing SPC services.'<sup>8</sup>

## Recommendations

- i. The committee has asked how the Mayor of London can support better end of life care for all Londoners. We believe there are a number of things he can do, in particular, he can provide leadership that inspires the relevant decision makers to drive much needed improvements forward.
- ii. There have undoubtedly been improvements in access to palliative and end of life care services by people with MND in recent years. As described above, this is particularly the case with regards to access to specialist palliative care services. This is a significant success and should be celebrated.
- iii. Funding and leadership have been key to this success. The National End of Life Care Strategy for England, published by the DH in 2008, was accompanied by £286m in 2009-10 and 2010-11. Alongside this, the NHS introduced the National End of Life Care Programme, with dedicated staff and an extensive programme of work. Together, these initiatives drove significant change in commissioning, service delivery and practice at the local level.
- iv. Devolution of decision making power to the local level, as per the new NHS structure, can and will drive improvements to palliative and end of life care in some localities. Some CCGs are choosing to prioritise care for their populations approaching the end of life. Usually this is where there is a commissioner personally committed to championing this area of care. In other CCGs, end of life care is overlooked almost entirely. This creates unfair local variation and inequity.
- v. In order to mitigate this risk, and to better support end of life care for all Londoners, we recommend that the Mayor of London take the following action:
  1. Provide ongoing assessment and oversight of how CCGs and local authorities are performing on end of life care, particularly in reference to reducing inequalities (for example by casting a spotlight on inequity by diagnosis)
  2. Champion end of life and palliative care and celebrate good practice so that commissioners who are not currently investing in services are encouraged to do so
  3. Write to health and wellbeing boards urging them to include end of life care in their strategies. The committee has noted that 11 London boroughs currently omit this from their plans entirely
  4. Help to bring health and social care commissioners together and to find innovative ways of working together. End of life care is too often considered

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<sup>8</sup> Ibid

the sole responsibility of the NHS, however many of the needs people have towards the end of life are social in nature<sup>9</sup>

5. Work with local authorities to ensure the housing needs of people with MND are met promptly and effectively. Particular emphasis should be put on ensuring housing adaptations are made in a timely manner, to enable people to receive care in their own homes, if that is their preferred setting
6. Support calls for 24/7 access to SPC telephone support and 9am to 5pm access to face-to-face visiting to be made available, in line with national guidance, across the capital
7. Support initiatives that have been shown to deliver on choice and quality, such as Coordinate My Care, which is a way of sharing patient information between services, particularly towards the end of life. Particular attention should be paid to extending uptake by people with conditions other than cancer, such as MND, particularly in the North East of London<sup>10</sup>
8. Lead Londoners in talking more openly about their wishes and preferences for the end of life. The population should be empowered to have open and honest conversations, in order to ensure that professionals are able to truly meet the needs of people at the end of their life, and that the issue is the high priority it should be with decision makers. The Mayor and London Assembly should proactively participate in the next Dying Matters awareness week in May 2016, to help Londoners to have open conversations about their wishes.

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<sup>9</sup> [www.lgiu.org.uk/wp-content/uploads/2012/11/A-Good-Death-the-role-of-the-local-authority-in-end-of-life-care.pdf](http://www.lgiu.org.uk/wp-content/uploads/2012/11/A-Good-Death-the-role-of-the-local-authority-in-end-of-life-care.pdf)

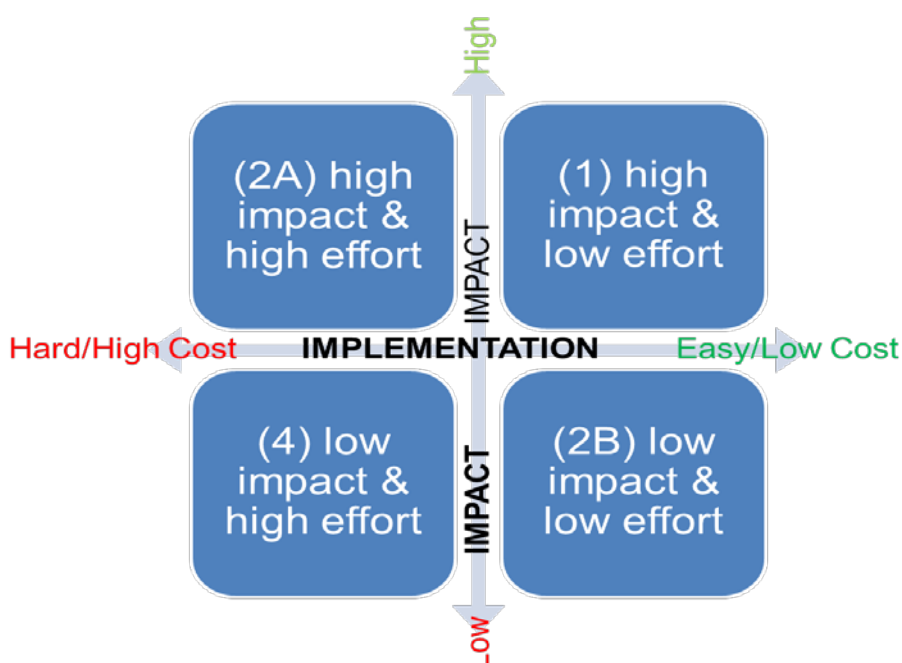
<sup>10</sup> <http://coordinatemycare.co.uk>

## Pan-London End of Life Alliance Lay Representatives Board Statements: What could have the most positive impact on improving our experience of care?

This paper presents the pan-London End of Life Alliance Lay Representatives Board's recommendations for priorities to focus on which are considered to have the most positive impact on the experiences of terminally ill patients and their carers across London.

**Strategic groups with a remit for improving end of life care for patients and carers across London** such as the London Social Care Partnership End of Life Care Network and Clinical Network for End of Life Care **are requested to review and respond to the Lay Representatives Board with how priorities identified are being or will be addressed by their groups.**

To establish these priorities the pan-London End of Life Alliance Lay Representatives Board reviewed their launch statements (Appendix 1) using an activity priority matrix scoring tool (illustrated in Figure 1). The principle behind using the tool within this context being – to score each activity on the degree of impact the activity will have on improving patients and carers experiences vs the effort involved in implementing it successfully taking into account resources and finances.



**Figure 1:** Activity priority matrix tool used to prioritise activities considered to have the most positive impact for terminally ill patients and their carers across London

The outcome of the action prioritising exercise is illustrated on the next page. In particular strategic groups are asked to focus on addressing activities detailed in categories 1 and 2A envisaged to have the most positive impact for terminally ill patients and their carers across London. Category 1 being 'quick wins' and category 2A being those with high impact worth prioritising but which require greater effort to implement and may be longer term projects.



## **1. High impact activities considered easier to implement**

- We are actively engaged in preparing our own holistic care plans in which our individual voices, needs and preferences are heard. These care plans should reflect our individuality including culture, ethnicity, spiritual beliefs, religion and gender. In particular, those with high-need long-term conditions should be prioritised for advanced care planning to support ensuring the transition to a terminal phase is positively managed.
- We are supported by professionals who provide advice, support and information both in terms of what is practicable but also to empower us as both patients and carers to explore purpose and meaning in order to derive maximum life quality.
- We are supported through social media forums and through community representatives acting as facilitators to enable us to talk as a community more openly about death and end of life.
- Professionals from all disciplines are well trained to ensure terminally ill patients and their carers' needs are met in particular
  - GPs are effectively trained in identifying end of life patients at an early stage and sensitively managing 'difficult conversations' (GPs should not be seen as the sole solution for this).
  - Professionals from all disciplines including those in social care and care homes are trained to confidently manage meeting the individual care preferences of End of Life patients and their carers. For example, cultural sensitivities are respected in terms of cooking techniques.
- We receive continuity of care in which we communicate information once which is supported in time by systems which play a role in ensuring that everyone has access to the most up to date and accurate information about us. For example, when discharging a patient from hospital into the community, discharge reports need to be issued promptly in which content has taken account of consultation with relevant agencies, carers and (our) holistic needs.
- The use of pharmacists and pharmacies is optimised to support our clinical and palliative care needs.

## **2A. High impact activities considered harder to implement**

- Our holistic care plans in which our individual voices, needs and preferences are recorded are respected, implemented effectively and acted on sensitively.
- We are given equity of access to care across London i.e. good end of life care is equally accessible to everyone across borough boundaries and for cancer and non-cancer patients alike. In particular we do this by actively reaching out to minority groups and sectors of society who have been marginalised or socially excluded such as BME communities, vulnerable adults, people who are homeless or have issues with substance misuse, the LGBT community, and others.
  - In order to achieve this most effectively more innovative techniques to reach out to people need to be considered – for example where language barriers exist (and an appropriate interpreter is not available) patients could be assisted to reflect their needs with pictures/signs.
- We are empowered as carers to support our loved ones and professionals equally support us and our holistic needs as individual needs in our own right.
- When we are in crisis we have access to high quality out of hospital care 24 hours, seven days a week capable of guaranteeing good responsive services which uses NHS resources most effectively.
- We minimise social isolation of those dying by actively engaging communities to provide a network of support.
- We are cared for by professionals from all disciplines who are appropriately recruited based on their natural aptitude for caring and are inspired by role models and a supportive management/leadership culture to ensure patients and their carers' needs are met.

## **2B. Low impact activities considered easier to implement**

The lay representatives board did not identify any issues they considered of low impact that would be easy or of low cost to implement.

## **4. Low impact activities considered harder to implement**

- We are inspired as Londoners to talk more openly about death and end of life to a sufficient degree to result in a positive change in how society responds to their own change in circumstance, or those of people around them.

## Appendix 1: Pan-London End of Life Alliance – Lay Representatives Board Launch Statements

*Facing the transition to life's end is an emotionally vulnerable time for us as patients and for those of us who love them. We want professionals to recognise this is often a traumatic period in our lives and a memory of a “good” death can support us as carers<sup>1</sup> to feel consoled after they have died, whereas the memory of a death involving unnecessary suffering can often be a long-term painful memory.<sup>2</sup>*

### What does “good” look like for End of Life for us (patients and their carers)?

- To be supported by professionals, surrounded by people who love us and supported to be at peace with our circumstances and to maximise our life quality.
- To be cared for by professionals with compassion, care, commitment, competence, courage, communication and good listening skills.
- To have our (patient and carer’s) voices, needs and preferences heard, respected and acted on sensitively. Taking into account our individuality including culture, ethnicity, gender, spiritual and religious beliefs to ensure care is tailored to the needs of us as individuals in London. For example, efforts are made to actively reach out to our community members who come from minority groups or who have been marginalised or socially excluded by society such as homeless people, or people with dementia who may be challenged in communicating their needs, or the BME community where language barriers may exist<sup>3</sup>.
- To receive a high quality experience of care based on our individual needs and preferences; rather than care delivered based on assumptions about what we prefer e.g. to die at home.
- To be actively engaged in 1:1 discussions about our *holistic* emotional, physical, cultural and spiritual needs and preferences through a mechanism of advanced care planning. For example, our preferences about the issue of DNRs should be handled with sensitivity at all times and our choices documented and respected. In addition, where we have complex needs and multiple health conditions we are treated by taking into account these various conditions, not just our primary diagnosis.
- To have seamless continuity of care at all times in which all organisations work together in a holistic manner and we only need to communicate information *once* rather than needing to repeat ourselves i.e. ensuring that everyone has access to the most up to date and accurate information about us.

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<sup>1</sup> The pan London End of Life alliance lay representatives board emphasised where a reference to carers has been made in these statements it refers to “individuals of significance to the patient” not only those identified as next of kin, family or partner.

<sup>2</sup> Statements highlighted in blue were emphasised for their importance by the pan London End of Life alliance lay representatives board.

<sup>3</sup> Other examples include the traveller community, the hard of hearing, blind, mentally ill and people with learning disabilities.

## What are the biggest challenges to achieving this?

- A proportion of health and social care professionals have a *disrespectful attitude* to us at times which is *unacceptable* during an often traumatic period in our lives – largely we consider this is a consequence of either recruitment mismatches, gaps in their training needs, or their institutional management and leadership culture which does not inspire better behaviour. For example, carers who often are most sensitive to the patient's needs are occasionally told by the medical team, against the patient's wishes, to leave the area away from view of the patient to enable the medical team to focus on carrying out the caring/nursing procedures.
- Many of our community members are socially isolated and lack support from their family or a community network.
- Our care currently is often reactively managed and fragmented rather than care we have actively been involved in planning and which is joined up.
  - Currently, there are innumerable 'missed opportunities' to discuss wishes for the future for those of us who are 'at a higher risk' of dying.
  - The links between health and social care are often criticised as less effective than they need to be, and should be strengthened, especially in discharge from hospital into the community. Transitions between urgent and emergency care, longer term and intermediate care and end of life care all suffer from a lack of overall coordination between agencies. Capacity or logistical issues in one service can often adversely impinge on another, without any corresponding means of adjustment.
- We need a culture change in terms of people more openly talking about dying to support shifting the 'taboo' that often surrounds it.
- We are aware there is often inequity of access to high quality care across London, especially for minority groups or sectors of society who have been marginalised or socially excluded such as BME communities, vulnerable adults, people who are homeless, the Lesbian, Gay, Bisexual, and Transgender (LGBT) community and others. For example in London considering 22%, or 1.7 million residents, use a main language other than English we need to ensure language is not a barrier for "good" care.
- Inequity of care is also a key issue for those with a non-cancer terminal diagnosis.

## What could have the most positive impact on improving our experience of care?

- *We are actively engaged in preparing our own holistic care plans in which our individual voices, needs and preferences are heard, respected and acted on sensitively. These care plans should reflect our individuality including culture, ethnicity, spiritual beliefs, religion and gender.*
- *We are given equity of access to care across London i.e. good end of life care is equally accessible to everyone across borough boundaries and for cancer and non-cancer patients alike. In particular we do this by actively reaching out to minority groups and sectors of society who have been marginalised or socially excluded such as BME communities, vulnerable adults, people who are homeless or have issues with substance misuse, the LGBT community, and others.*
  - In order to achieve this most effectively more innovative techniques to reach out to people need to be considered – for example where language barriers exist (and an appropriate interpreter is not available) patients could be assisted to reflect their needs with pictures/signs.
- We are supported by professionals who provide advice, support and information both in terms of what is practicable but also to empower us to explore purpose and meaning in order to derive maximum life quality.
- We are empowered as carers to support our loved ones and professionals equally support us and our holistic needs as individual needs in our own right.
- When we are in crisis we have access to high quality out of hospital care 24 hours, seven days a week capable of guaranteeing good responsive services which uses NHS resources most effectively.
- We receive continuity of care in which we communicate information once which is supported by electronic systems which play a role in ensuring that everyone has access to the most up to date and accurate information about us. For example, when discharging a patient from hospital into the community, discharge reports need to be issued promptly in which content has taken account of consultation with relevant agencies, carers and (our) holistic needs.
- We are supported as a community to talk more openly about death and end of life for example through soap operas covering such story lines or by having celebrity spokespeople.
- We minimise social isolation of those dying by actively engaging communities to provide a network of support.
- We optimise the use of pharmacists and pharmacies to support our clinical and palliative care needs.
- We are cared for by professionals from all disciplines who are appropriately recruited based on their natural aptitude for caring, who are well trained and are inspired by role models and a supportive management/leadership culture to ensure patients and their carers' needs are met in particular
  - GPs are highly skilled in identifying end of life patients at an early stage and are confident in sensitively managing 'difficult conversations' but GPs are not seen as the sole solution for this.
  - Professionals from all disciplines including those in social care and care homes are skilled to confidently manage meeting the individual care preferences of End of Life patients and their carers. For example, cultural sensitivities are respected in terms of cooking techniques.

## Appendix 1: Guidelines and standards to follow to support delivery of “good” End of Life care.

- NICE Quality Standard: End of life care for adults (QS13). <http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-gs13>
- NICE Guide for commissioners on End of life care for adults, 2011. <http://publications.nice.org.uk/guide-for-commissioners-on-end-of-life-care-for-adults-cmg42/1-commissioning-services-for-end-of-life-care-for-adults>
- “Homelessness and End of Life Care” information pack jointly developed by Marie Curie and St Mungo’s. <http://www.mariecurie.org.uk/Documents/Commissioners-and-referrers/HomelessReport.pdf>
- End of life care strategy: promoting high quality care for all adults at the end of life (Department of Health 2008).
- End of life care strategy: quality markers and measures for end of life care (Department of Health 2009).

## Pan-London End of Life Alliance

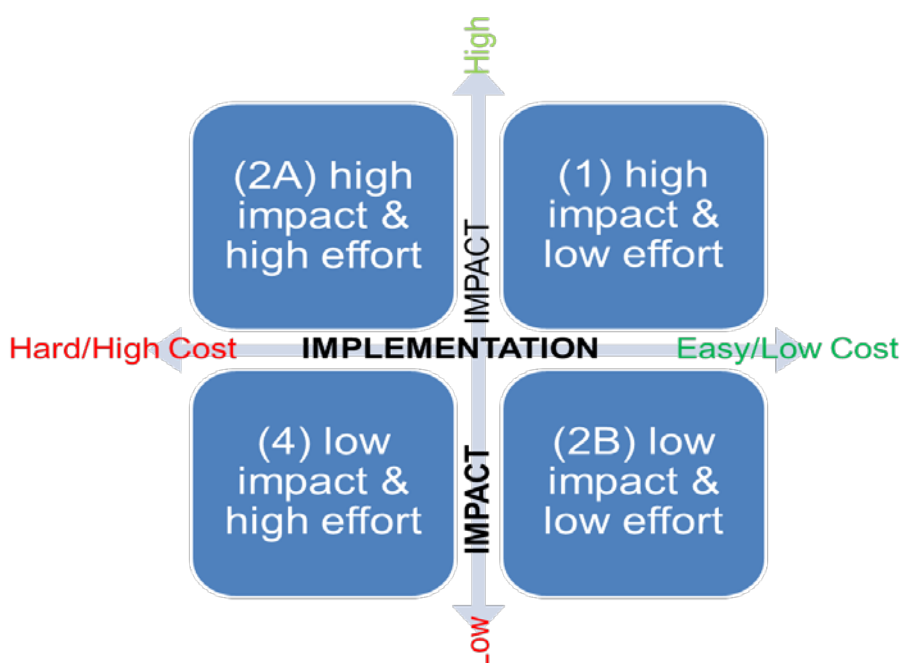


## Pan-London End of Life Alliance Lay Representatives Board Statements: What could have the most positive impact on improving our experience of care?

This paper presents the pan-London End of Life Alliance Lay Representatives Board's recommendations for priorities to focus on which are considered to have the most positive impact on the experiences of terminally ill patients and their carers across London.

**Strategic groups with a remit for improving end of life care for patients and carers across London** such as the London Social Care Partnership End of Life Care Network and Clinical Network for End of Life Care **are requested to review and respond to the Lay Representatives Board with how priorities identified are being or will be addressed by their groups.**

To establish these priorities the pan-London End of Life Alliance Lay Representatives Board reviewed their launch statements (Appendix 1) using an activity priority matrix scoring tool (illustrated in Figure 1). The principle behind using the tool within this context being – to score each activity on the degree of impact the activity will have on improving patients and carers experiences vs the effort involved in implementing it successfully taking into account resources and finances.



**Figure 1:** Activity priority matrix tool used to prioritise activities considered to have the most positive impact for terminally ill patients and their carers across London

The outcome of the action prioritising exercise is illustrated on the next page. In particular strategic groups are asked to focus on addressing activities detailed in categories 1 and 2A envisaged to have the most positive impact for terminally ill patients and their carers across London. Category 1 being 'quick wins' and category 2A being those with high impact worth prioritising but which require greater effort to implement and may be longer term projects.

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- We minimise social isolation of those dying by actively engaging communities to provide a network of support.
- We are cared for by professionals from all disciplines who are appropriately recruited based on their natural aptitude for caring and are inspired by role models and a supportive management/leadership culture to ensure patients and their carers' needs are met.

## **2B. Low impact activities considered easier to implement**

The lay representatives board did not identify any issues they considered of low impact that would be easy or of low cost to implement.

## **4. Low impact activities considered harder to implement**

- We are inspired as Londoners to talk more openly about death and end of life to a sufficient degree to result in a positive change in how society responds to their own change in circumstance, or those of people around them.

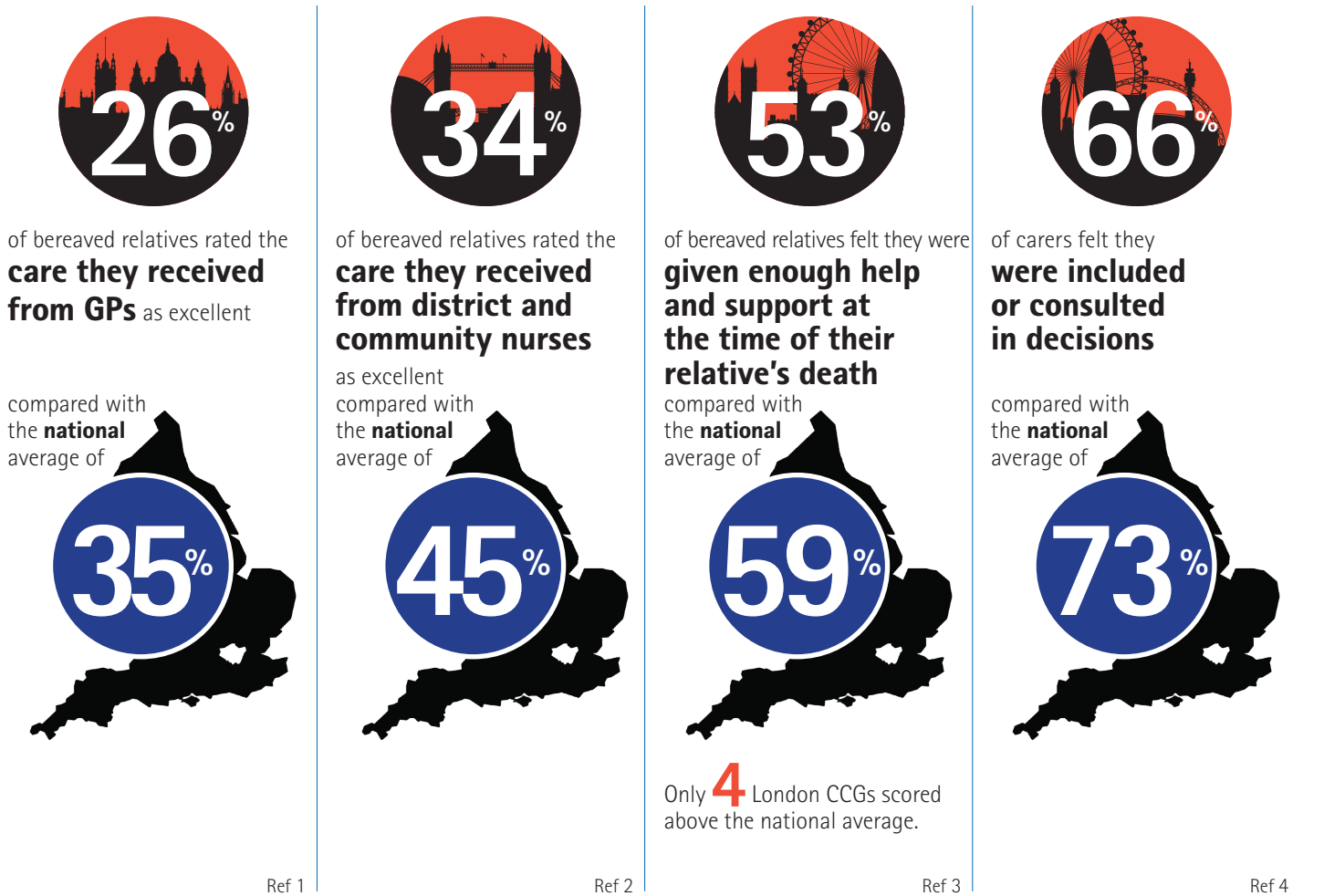
# DYING IN LONDON WE MUST DO BETTER

The quality of end of life care which people living in London receive currently under-performs against the national average, showing a huge variation against a range of indicators.

On average in London:

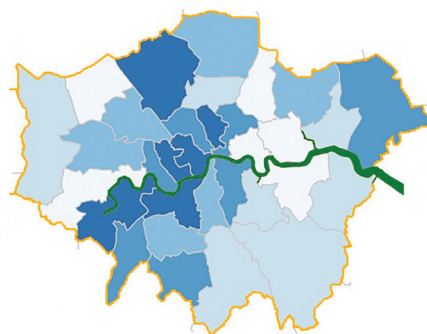
The **Pan-London End of Life Alliance** is a social movement working to improve the care that terminally ill people and their families receive in the capital.

Guided by a board of committed lay representatives, we are identifying key areas for improvement to make services work for the people who use them and to reduce variation.



## Huge variation in overall quality of care across London

The second best rated CCG in the UK is in London; and so is the worst.



% rating quality of care as outstanding or excellent

- 26.5 – 32.8
- 32.9 – 35.2
- 35.3 – 37.1
- 37.2 – 45.1
- 45.2 – 56.3

Ref 5

Follow our progress  
[mariecurie.org.uk/alliance](http://mariecurie.org.uk/alliance)

Compare UK-wide stats on end of life care  
[mariecurie.org.uk/atlas](http://mariecurie.org.uk/atlas)

Reference: 1, 2, 3 and 5, Marie Curie Atlas (source: combined data from the ONS Survey of Bereaved People VOICES, 2011-12).  
Reference: 4, Health and Social Care Information Centre, (Carers survey, 2012-12).

## Pan-London End of Life Alliance



Charity reg no. 207994 (England & Wales), SC038731 (Scotland) T249d



Dear Georgina,

Thank you for contacting our CCG last week seeking views on EOL service provision in Redbridge. We understand this a London wide review looking at service provision gaps with view of improving services for wider consistency.

EOL is a significant priority within Redbridge and at present we have a joint improvement plan underway further to a recent review of our services. We work very closely with the Redbridge local Authority, our provider North East London NHS Foundation Trust and St Francis Hospice, we have strong commitment from all partners and currently looking at enhancing service level support to our residents. We are also working collaboratively with Barking and Dagenham and Havering CCGs for regional consistency.

If you would like further information on our current work, please get in touch so we can provide you with further details. In the meantime, I trust the response below is useful for your investigation. Given our current work, we would find it highly useful to see your final investigative findings .

What are the main challenges for ensuring good quality end of life care for older Londoners who live alone?

- Proactive recognition of people with uncertain recovery
- Discussion offered by health and social care practitioners when a person is approaching end of life
- Consistency in levels of support regardless of primary diagnosis
- Commitment to development of shared electronic records accessible across the health and social care economy.

We have locality areas within the borough with elder population and we hope our current online care plan work which includes all partners in patient care should improve this aspect of service.

**These individual with limited family and social support, will need to be identified early on and offered a holistic care plan.**

What additional challenges are faced by other groups, such as people from BAME communities?

Working through 'taboos' and ensuring difficult conversations can be held to provide appropriate culturally sensitive responses/support.

We work collaborative with our Community Voluntary Sector colleagues to address culturally sensitive aspects of care. EOL has various impacts depending on an individual's religious beliefs and these specific areas need tailor made approaches as part of the care plan.

What healthcare and social support is needed to ensure that more people die in their place of choice?

- Timely discussion with people and their family before their condition begins to rapidly decline

- Improve integration and handover arrangements with community based services including adult social care and between other hospitals.

Again, this will require strong partnership working between all who take part in the patient's care. Training and development needs of these care providers need to be met to offer advanced communication skills so professionals can discuss future planning with the patient and their family.

How is the quality and availability of end of life care affected by the diagnosis received?

The model for cancer care is not reflected in other conditions particularly neurological conditions where there can be variable trajectory of decline. We have work underway to improve EOL for all conditions such as Heart Failure, Dementia and COPD.

How well equipped are London's health and social care providers to deal with a rising and ageing population?

There are many financial and capacity issues to be managed/resolved at national and local level. Redbridge CCG considers these limitations when setting annual Commissioning Intentions.

How can the Mayor support better end of life care for all Londoners?

- Proactively support initiatives to raise awareness of the public around planning for end of life care taking account of age, disability and those facing communication difficulties
- Work with local Health & Wellbeing Boards to promote implementation of the 'Ambitions for palliative and end of life care framework'

Please do not hesitate to contact me should you have any further queries.

Kind regards

A large black rectangular redaction box covering the signature and name of the sender.

Redbridge Clinical Commissioning Group  
Becketts House, 2-14 Ilford Hill, Ilford, Essex IG1 2QX

## Submission to the London Assembly Health Committee: End of Life Care Review

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### About Royal Trinity Hospice

1. Royal Trinity Hospice provides skilled, compassionate care and support to people with progressive, life-limiting illnesses and those close to them. We support people living in our central and south west London community, at home and at the hospice. Our care is centred on the unique needs of each individual and those close to them.
2. Our catchment area covers all or part of 7 London boroughs: Wandsworth, Lambeth, Merton, Richmond, Hammersmith & Fulham, Kensington & Chelsea, and Westminster. All our services are provided free of charge to patients and their families. We receive under 30% of our funding from the NHS, and we rely on donations to raise the remaining £8 million every year that is needed for our services to continue.
3. Trinity has been providing this vital support for 125 years - last year, we cared for 1,500 people and provided emotional and practical support to their family and friends. We also offer education and training on end of life care and provide support to health and social care professionals who do not have expertise in looking after people at the end of their lives.

### What are the main challenges for ensuring good quality end of life care for older Londoners who live alone?

4. In our experience, the key challenge in this area is ensuring people are referred - and referred early enough - to those organisations which can make a difference to their lives, particularly when they socially isolated.
5. Like many hospices, Trinity offers a range of services and support to individuals well before they need care at the end of their lives. Some of our services are particularly of benefit to people who do not have family at home: for example, we offer befriending - volunteers who visit patients either to give carers a break, or to give patients some much-needed company - and various group wellbeing activities. But we also offer support that can be hard to access without a carer advocating for the patient's needs, such as counselling and emotional support, practical help with matters such as Wills, benefits and financial advice, or physical therapy to keep people mobile and independent for as long as possible.

6. However, not enough health and social care professionals, or those working with older Londoners such as voluntary sector organisations, are confident enough in their knowledge of hospice care, or end of life care services, to know that they can refer people to us well before their last days.
7. Without family to advocate or to provide informal care, older Londoners living alone are more vulnerable to the vagaries of a health system that has patchy knowledge and experience of palliative care.
8. In addition, while a plurality of providers can provide a depth and breadth to care, it can also add to the complexity of navigation, especially for those in isolation. For example, assessment forms are often duplicated, and in many areas there is not a single point of contact. Royal Trinity Hospice is working with the CCG and community services provider in Wandsworth to pilot an End of Life Care Coordination Centre which overcomes these problems. As well as offering a single point of contact over extended hours, the centre provides trouble-shooting, as well as advice and signposting, for patients navigating the health and care system.

### **What additional challenges are faced by other groups, such as people from BAME communities?**

9. Like many healthcare providers, Royal Trinity Hospice believes there is much more work to be done to ensure all sections of the community are able to access specialist palliative care services.
10. Trinity has been working with BAME community organisations in central London to understand the issues faced by these groups. Many first or second generation immigrants or refugees come from countries where hospice care does not exist, and we have found many unaware of what hospice care can offer in this country. So they are more reluctant to accept a referral if it is offered to them.
11. We are also pioneering an approach with one section of underrepresented service users: the LGBT community, whom we know are less likely to access specialist palliative care services, and will do so later, when they are less well. Trinity was the first hospice to march at London Pride in 2014 and 2015; we have introduced Stonewall diversity training for our staff and we have set up an 'LGBT Friends of Trinity' group to help us market our services and support as LGBT-friendly.

## **What healthcare and social support is needed to ensure that more people die in their place of choice?**

12. One of the biggest challenges in supporting people's choice about where they die is the bureaucratic and funding complexities in the health and social care systems.
13. The division within and between providers of care to people at the end of life is exacerbated by different funding mechanisms between health and social care, and differences in commissioning between acute and community providers. Navigating different funding systems on behalf of our patients is not only time-consuming but frequently delays the provision of effective community-based care.
14. As pressures increase on statutory budgets, we find there is less incentive for funders to work together, and we often find ourselves in the middle, trying to locate responsibility for a patient's care package with either the NHS or local authority, and frequently offering our own resources to fill the gap left by statutory services.
15. Personal budgets offer opportunities for some people with life-limiting conditions to overcome these barriers between different health and social care providers. However, these will not work for many of those accessing palliative care, as they take a long time to set up, and the administration required is complex. We believe a more integrated and flexible approach to funding care that enabled resources to be pooled between health and social care, and between acute and community providers, would provide a more responsive service to people approaching the end of life.

## **How is the quality and availability of end of life care affected by the diagnosis received?**

16. Too often, the perception is that hospices and other specialist providers are only for people with cancer, and that reflects both the history of the sector, but also that cancer is relatively easier to prognosticate than many non-cancer diagnoses.
17. However, Royal Trinity Hospice cares for patients with any life-limiting illness, not just cancer. In our community service, where we provide the majority of our care, just over 1/3<sup>rd</sup> (34%) of our patients have a non-cancer diagnosis; whereas on average only 24% of patients in London palliative care providers do not have cancer. Trinity has a dedicated dementia service in two of our CCGs actively to promote and encourage referrals for dementia patients, as well as improving the quality of end of life care provided to dementia patients in the community.

18. For those patients who are fortunate enough to be referred to hospices, the quality and availability of the end of life care they receive is not affected by diagnosis. But as above, the issue is often getting health and social care professionals to refer early and appropriately to hospices, when they are often not confident themselves of their own knowledge of end of life care.

### **How well-equipped are London's health and social care providers to deal with a rising and ageing population?**

19. The very tight public sector funding environment is putting phenomenal pressure on health and social care providers, even without the rise in demand for their services.

20. However, we believe that the complexity of the delivery and funding system for end of life care makes the problem more acute, with many of London's statutory health and social care service providers being unable to respond to the demographic pressures on the system.

### **How can the Mayor support better end of life care for all Londoners?**

21. The Mayor of London has a vital role as a figurehead promoting health and well-being, and reducing health inequalities between people in London.

22. Royal Trinity Hospice believes that one of the biggest inequalities in end of life care is between those who receive expert compassionate care of the kind we provide, and those who do not have access to hospice care at the end of their lives.

23. If the Mayor were actively to promote hospice care and the importance of specialist end of life care in London as part of his strategy to reduce health inequalities, this would be a welcome initiative aimed at reducing this inequity in access.

### **Conclusion**

24. We would be happy to provide the Committee with more detail on any aspect of this submission.

**Royal Trinity Hospice**  
**November 2015**

Dear Lucy

The London Cancer Alliance Palliative Care Group supports the comments and evidence provided by Dr Fliss Murtagh. In particular, the pan-London report demonstrates that the provision of specialist palliative care availability does not meet NICE guidance from 2004 and this as Fliss points out, has an impact on the ability to look after people well in and out of hospital. It also offers an opportunity for cost saving with additional resources as appropriately resourced specialist palliative care teams could do more to avoid unnecessary admissions and facilitate early discharge at the end of life.

The VOICES national bereavement survey demonstrates that London lags behind the rest of the country in the quality of end of life care as perceived by those close to the patient. ([http://www.ons.gov.uk/ons/dcp171778\\_399897.pdf](http://www.ons.gov.uk/ons/dcp171778_399897.pdf) and attached). We believe the London Mayor can change this inequity in the quality of end of life care for Londoners by providing a steer to commissioners, providers of health and social care and others working towards excellence in this area.

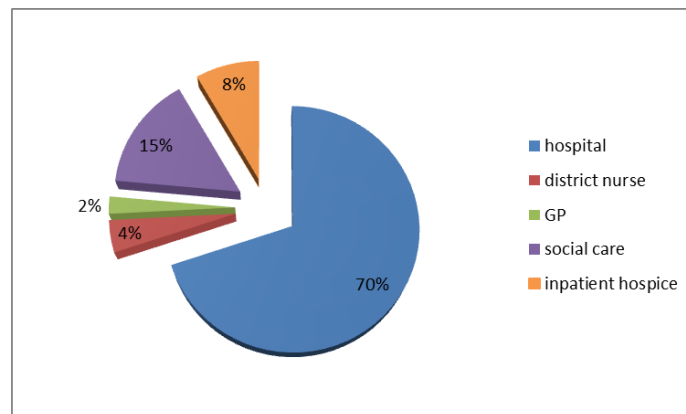
Regards

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## The context of end of life care:

- Approximately 27% of NHS spend is in last year of life
- Hospital costs are **by far** the largest cost elements of end of life care. In last 3 months of life, average cost per person who died are:
  - £4,600 for hospital costs (mostly emergency admissions)
  - *About £280 for DN costs (although wide variance)*
  - *About £150 for GP visits (average 4.6 visits but cancer)*
  - £1,000 for LA-funded social care costs (Georghiou and Bardsley, 2014 Nuffield Trust)

## Average health and social care costs in last three months of life:



(Georghiou and Bardsley, 2014 Nuffield Trust)

## What do palliative care teams do?

- They deliver palliative care as their **core daily work**, in **multidisciplinary teams** with **specialist skills and expertise**.
- They explicitly provide care to both **patients** and **families** with life-limiting progressive disease
- They deliver both:
  - **direct care** to patients and families
  - **indirect care** by supporting other professionals to deliver direct care

## Does palliative care work?

There is consistent and comprehensive evidence for better outcomes following palliative care, including:

- Better symptom control
  - Improved communication
  - Better emotional well-being, less depression (patients and families)
  - More satisfaction with care (patients and families)
  - Higher quality of life (patients and families)
- (Higginson 2003, Abernethy 2008, Garcia-Perez 2009, Temel 2010, Murtagh 2014)

## Palliative care may also offer improved survival:

- US-based randomised controlled trial of palliative care for those with metastatic lung cancer, median survival 11.6 months with palliative care versus 8.9 months without palliative care
- 2 to 3 month improvement in survival
- Similar survival gain to cis-platin based chemotherapy



- Less interventions, less chemotherapy (Temel 2010)

### **Is palliative care cost-effective?**

- Recent comprehensive and systematic review shows that those receiving palliative care consistently cost less in terms of their overall healthcare (Smith, Normand 2013 *Pall Med*)
- Most evidence relates to direct costs
- Little consideration of informal care costs (largely borne by families)
- Most of the potential cost savings relate to reduction in use of acute hospital-based healthcare

### **Can palliative care make a difference across the wider healthcare system?**

- Effect of 11 community based palliative care teams:
  - across all teams, reduction in emergency department visits and hospital admissions
  - reduction of about 1/3<sup>rd</sup> in last two weeks of life alone
  - teams were multidisciplinary, with specialist expertise, providing direct and indirect care (exact configuration of team less important)

(study from Canada, Seow 2014 BMJ)

### **Can hospital palliative care consultation make a difference?**

Synthesis of 10 studies:

- Inpatient palliative care consultation programs have been shown to save hospitals money and to provide improved care to patients with serious illness.
- Clear pattern of cost-saving following hospital palliative care consultation

(May 2015, Journal of Palliative Medicine)

### **Can earlier hospital palliative consultation make a bigger difference?**

- Results from the economic evaluation of 969 patients:
  - Earlier palliative care consultation during hospital admission is associated with lower cost of hospital stay for patients admitted with an advanced cancer diagnosis
  - Earlier consultation is associated with a larger effect on total direct cost
  - Intervention within 6 days is estimated to reduce costs by \$1,312 (14%) compared with no intervention and intervention within 2 days by \$2,280 (24%)

(May 2015 Journal of Clinical Oncology)

### **In conclusion:**

- **Does palliative care work? Yes**
- **Is it cost-effective? Yes, highest impact if provided early, and best evidence from hospital setting.**
- **Palliative care is likely to reduce overall health care costs through impact on emergency admissions and reduction in acute interventions towards end of life.**

## **1. What are the main challenges for ensuring good quality end of life care for older Londoners who live alone?**

One of the main challenges is *reaching* those older people who are living alone and who may be in poor health and have little knowledge of what their options might be in terms of end of life care (EOLC). In our experience, local authorities and their health and social service teams constantly talk about how difficult it is to reach the hardest to reach people who may be some of the most vulnerable and unsupported. The confidentiality and non-judgemental nature of our service means that The Silver Line is readily accessed by people who might be wary of approaching other services. As a consequence we are reaching some of the most lonely and isolated people across the country. Our staff (the vast majority of whom are trained volunteers) are talking to such older people and building trusting relationships with them. We would suggest that one of the main challenges is not having enough health, social care or voluntary and community sector (VCS) options to offer people who are in a position to need them towards the end of their lives. We need to address this first before we raise any expectations. A recent evaluation of The Silver Line service by Anglia Ruskin University states,

***“...The research concludes that The Silver Line is successful in accessing the loneliest and most socially isolated people...”***

We would ask the Mayor to think about bringing together a collection of services for older people, such as ours and the Samaritans, which can assist with the challenge London’s health and social care system is facing in terms of EOLC and reaching the most lonely and isolated people across London.

## **2. What additional challenges are faced by other groups, such as people from BAME communities?**

Cultural differences in terms of EOLC and feelings that their families should be providing support at this time of life and embarrassment that the person finds themselves on their own without any familial support are challenges that older people, particularly from BAME communities might face. Building trusting relationships with people from our BAME communities is an essential part of beginning to overcome cultural barriers. Educating the younger generations within those communities about what is available in terms of EOLC is another essential. The development of the EOLC health, social care and VCS market will be needed in order for personnel to be in a position to be able to advise on what is available before approaching these diverse cultural communities with available options.

## **3. What healthcare and social support is needed to ensure that more people die in their place of choice?**

Market development support across the private, statutory and voluntary and community sectors to increase the number of organisations who are able to provide appropriate end of life / palliative care to people from a variety of different communities in their preferred place is an important first step. That support might be commissioning organisations such as

Marie Curie and Macmillan Cancer and other palliative care charities to provide the kind of EOLC service that can't be provided by health and social care services. Training health and social care staff to be able to provide palliative care and ensuring that there is appropriate availability of such staff and staff time for the delivery of 'statutory' palliative care services. If this isn't possible then there is a need to ensure that voluntary and community sector providers aren't just expected to be available without appropriate commissioning or funding arrangements.

#### **4. How is the quality and availability of end of life care affected by the diagnosis received?**

Some life limiting and terminal conditions appear to have more 'obvious' and available support attached to them. Cancer being one. When we think of end of life care we tend to think of organisations like Marie Curie and Macmillan Cancer Support as health professionals are more likely to be able to 'estimate' the life expectancy of a patient diagnosed with cancer. There needs to be more availability of EOLC for all kinds of diagnosed life threatening conditions. We're sure that there are a number of other palliative care organisations who are providing good EOLC but who aren't attracting publicity. The Samaritans also plays a crucial part in end of life care for people who have been diagnosed with a terminal condition who are in need of emotional and practical support to manage their way through this time.

#### **5. How well equipped are London's health and social care providers to deal with a rising and ageing population?**

London's health and social care providers and voluntary and community sector providers are having to adapt and develop their services to meet the needs of an ageing population. With the continued reduction in local government funding, the budgetary and human resource demands of the Care Act and the increasing pressure of delivering services to an ageing population, local government is under pressure. The VCS is well aware of the difficulty central and local government has in evidencing the impact of preventative services but, with an aging population more needs to be done in this area as helping our older residents to stay as physically, mentally and emotionally well for as long as possible is the only way of preventing them from having to access expensive services until absolutely necessary. There is evidence to suggest that people suffering from long term conditions are more likely to become depressed and less able to manage their conditions which can result in the unnecessary reliance on health and social care services.

#### **6. How can the Mayor support better end of life care for all Londoners?**

The Mayor can support better end of life care for Londoners by helping to develop the EOLC and palliative care provider market in the capital. This could be in terms of funding for the extension of existing, or the development of new, services. Being cognisant of the fact that

the majority of EOLC providers are charities who are under an on-going pressure to raise money in order to survive. A rethink of the way in which these organisations are funded or commissioned in order to provide more long term security and allow them the chance to think about future development opportunities. The third sector has experience and expertise in this sensitive area and could/should be working more closely with statutory sector partners to ensure that good EOLC becomes a seamless and accepted part of end of life care.

DRAFT

## **Palliative and End of Life Care Education and Training Strategy**

Dear [REDACTED]

I would like to make a submission to your investigation on behalf of Health Education South London, a Local Education and Training Board of Health Education England.

We have developed, with our expert stakeholders, a strategy for education and training to support good multi-professional end of life care in south London. Our investment decisions are guided by this strategy.

I hope this is of use and interest to the investigation.

With best wishes

[REDACTED]

[REDACTED]

**Health Education South London**

Stewart House | 32 Russell Square | London | WC1B 5DN

W. [www.southlondon.hee.nhs.uk](http://www.southlondon.hee.nhs.uk)

# Palliative and End of Life Care Education and Training Strategy

Meeting the education and training needs  
of all of the health & social care workforce  
involved in the end of life care of patients  
and the care of their carers

*‘How people die remains in the  
memory of those who live on.’*

Dame Cicely Saunders

February 2015

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## Foreword

While progress has been made in improving end of life care across the country since the publication of the EOLC Strategy in 2008, recent criticism about the use of the Liverpool Care Pathway for the Dying Patient and concerns around general care in hospitals and other care settings have highlighted the need for continued education of the health and social care workforce around the care of dying people. This strategy sets out to recommend the skills and competencies required by anyone caring for people at the end of life.

Dying is a normal part of the life course, however modern society has an expectation that death can be avoided (almost) at all costs. Our healthcare system is also designed to promote life at all costs and as a result when a person is facing a life limiting illness, they, their family and the professionals around them may not have experienced death before and they may not be fully equipped to deal with the necessary difficult conversations, or the uncertainty that the future may hold. Sadly, those reaching the end of their lives, either as a result of frailty and/or old age or as a consequence of the final stages of an illness, such as cancer, dementia, chronic obstructive pulmonary disease, chronic heart disease and/or a number of these co-morbidities, need to be afforded the same skilled and competent team of health and social care givers regardless of where they are cared for and whether or not the care provider is salaried or a volunteer.

End of life care needs to be delivered by people who are competent, confident, caring and compassionate, who feel supported in their role regardless of their professional status in the care delivery team. The care giver needs to feel valued in the delivery of their unique contribution to the care of the person reaching their end of life. This strategy focuses on the non-specialist palliative care workforce who are responsible for the majority of care for people in their last year of life; however consideration also needs to be given to the specialist palliative care workforce as they will be likely to provide care, support and advice to patients and families and non-specialists as well as providing much of the education and training. This strategy does not seek to address public education around death and dying, but local authorities and public health teams may wish to make links with Hospices and other specialist palliative care providers to develop strategies for public awareness.

This end of life care education and training strategy intends to set a direction for Community Education Provider Networks and care provider organisations in order to ensure they have staff who are competent, confident and compassionate in delivering good quality end of life care. The challenge for commissioners and providers is to recognise the need for education and training in end of life care in order to ensure people with life-limiting illness receive the best possible end of life care and those who are left behind after their death feel supported during a distressing time.

**Dr Nav Chana**

Clinical Adviser, Health Education South London

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## Executive Summary

The strategy has been developed following consultation with service users, health and social care professionals, commissioners, organisations involved in delivering education and those responsible for assuring the standards of education that are provided. It is endorsed by Health Education South London.

The recommendations from the Cavendish report (Cavendish, 2013), More Care, Less Pathway (DH, 2013), the Francis report (Francis, 2013) and One Chance to Get It Right (DH, 2014) have been considered and included in the training priorities included in this strategy.

This strategy aims to ensure that the health and social care workforce in South London have the skills and confidence to deliver holistic, compassionate care for dying people and their families regardless of where they are cared for. Implementation of the strategy will help to ensure incremental improvements and spread of high quality end of life care to all those who need it, regardless of pathophysiology, place of care or other characteristics which may have an impact on access to care.

The focus of the strategy is on the training of all grades and disciplines of generalist<sup>1</sup> and specialist staff who come into contact with dying people regularly. The strategy focuses on five themes for development within training:

- Communication skills
- Assessment
- Advance care planning
- Symptom management, comfort
- Family support, bereavement

Local training needs analysis will identify the training and skills development that should be commissioned by Community Education Provider Networks (CEPNs) and provider organisations; to support health and social care organisations to ensure staff have the right competencies, skills, attitudes and demonstrate compassion; Specialist Palliative Care and/or Education Providers should be appropriately commissioned<sup>2</sup> to ensure they have the necessary capacity to deliver education and training and to provide ongoing support to all those health and social care staff who are involved in the delivery of end of life care.

Any education delivery and skills development should be evaluated to demonstrate impact and value for money. This strategy includes some examples of programmes that are available and some new training which is in development. For further advice it is recommended that CEPNs and Care Organisations should liaise with their local education providers and Specialist Palliative Care Teams to explore opportunities to meet the training needs of their workforce.

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<sup>1</sup> For the purposes of this strategy, the term generalist refers to care providers who are not specialists in Palliative Care, however they may be specialist in other areas e.g. cardiology, dementia, respiratory medicine.

<sup>2</sup> Services may be commissioned locally and/ or regionally by individual provider organisations, CEPNs, CCGs, HESL etc.

## Introduction

Palliative and end of life care involves care to all those with any advanced, progressive, incurable illness. The aim of palliative and end of life care is to enable each individual to live as well as possible until they die; ensuring that the patient and family have their needs identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

The stages of the dying process are illustrated below, with care continuing beyond death to include last offices, care of the body, preparing for the funeral and bereavement support. Everyone who comes into contact with dying people and their families, regardless of care setting and/or role, needs to have an appropriate level of knowledge, and skills to provide competent, compassionate, sensitive care during the final phase(s) of a person's life.

### Timeframes in the dying process<sup>3</sup>

The End of Life

The Dying Phase



<b>At risk of Dying</b>	<b>Months</b>	<b>Short Weeks</b>	<b>Last Days</b>	<b>Last Hours</b>
in 6-12 months but may live for years	2-9 months	1-8 weeks	2-14 days	0-48 hours
Disease(s) Relentless Progression is less reversible. Treatment benefits are waning	Changes Underway Benefits of treatment less evident, harms of treatment less tolerable	Recovery less Likely  The risk of Dying is rising	Dying Begins  Deterioration is weekly/ daily	Actively Dying  The body is shutting down. The person is letting go

(Department of Health, 2013)

A workforce that is skilled and confident in the provision of palliative and end of life care underpins the development of reliable, responsible and sustainable services for people with

<sup>3</sup> See Appendix 1: End of Life Care Pathway

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life-limiting disease. The development of robust and appropriate education provision for palliative and end of life care is therefore vital to ensure high quality care for these people.

This strategy, in relation to the training of staff involved in palliative and end of life care of adults and children, has been created in recognition of this need. It will focus on the role of specialist palliative care practitioners and other experts in delivering education and training such as end of life facilitators and Macmillan GPs and outline the behaviours, attitudes, competencies and skills of health and social care staff who care for dying people and their relatives. The strategy outlines the training needs of Volunteers, Health & Social Care Assistants, Registered Health Care Professionals and Ancillary Staff who work in any care setting where dying people receive care. It builds on the education and training strategy drafted for SE London as part of the Marie Curie Delivering Choice Programme (SE London Palliative & End of Life Care Network, 2008); for more detail see Appendix 2.

This document aims to set out an education & training strategy which has been developed in partnership with service users, professionals from health and social care settings, commissioners of care, organisations involved in delivering education and those responsible for assuring the standards of education that are provided.

The strategy has been endorsed by Health Education South London and the Health Innovation Network<sup>4</sup> and aims to set out the long term vision for end of life care education and training to inform the prioritisation and planning of training for South London.

As different organisations will wish to implement this strategy according to their own individual priorities and education and training is funded through a number of different routes (e.g. CPPD, HESL support, ad hoc funds for specific projects, charitable grants, professional organisations and individuals); this strategy should help inform the overall plan from which they can identify existing resources or seek additional funding if required/appropriate.

## **The national context - motivation for change**

Health services in South London serve a population of approximately 3 million people and have an incidence of approximately 19,000<sup>5</sup> deaths per annum. In line with the rest of the country, over half of these people will die in hospital, despite the fact that when people are asked about their preferred place of care the majority of people will state a preference to be cared for at home or in a hospice (Gomes B et al, 2013).

Nationally, the proportion of deaths in the usual place of residence (DIUPR, deaths in own home or a care home) continues to increase and correspondingly the proportion of deaths in hospital is falling. The DIUPR figure for England was 43.7% in 2012, up from 37.9% in 2008 (Public Health England, 2013).

London has the widest variation for deaths at home. Sutton (15.9%) has the lowest percentage of home deaths while the City of Westminster has the second highest percentage (24.9%) in England (Public Health England, 2013).

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<sup>4</sup> The Health Innovation Network is the Academic Health Science Network for South London.

<sup>5</sup> National End of Life Care Intelligence Network gives crude death rate at 0.63% of London population (National End of Life Care Intelligence Network, 2013)

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An economic evaluation found evidence that implementing Electronic Palliative Care Co-ordination Systems (EPaCCS) affected place of death, with an extra 90 deaths occurring in the usual place of residence per 200,000 population each year above the underlying increase in rates experienced across England (Ipsos MORI Social Research Institute, 2011). People under hospice care are more likely to have had a conversation about their preferences for care in advance and to have their wishes met.

The majority of people die in hospital and it is important that quality end of life care is provided in all settings. Analysis of hospital care and local authority-funded social care services provided in the final 12 months of life for over 72,000 deaths in England found that 89.6% had some hospital care in the final year (Bardsley M, 2012). London has the highest percentage of deaths in hospitals (61%) and the lowest percentage of deaths in care homes (11.8%) (Public Health England, 2013).

The main causes of death can be broadly divided into 4 groups; cancer, organ failure, dementia/frailty and sudden death. Advances in treatment and demographic changes are already beginning to have an impact on the causes and complexity of death/dying, with more people suffering with one or more long term condition and frailty/dementia becoming more predominant. It is predicted that nationally, the death rate is likely to increase by 17% by 2030 (Department of Health, 2008); this is an additional 3,200 deaths per annum in S London. People who receive Specialist Palliative Care are more likely to die at home than those who do not; people over 85 and those with a non-cancer diagnosis are less likely to access Specialist Palliative Care, although this is increasing (National Council for Palliative Care, 2012).

The quality of care for people who are dying in hospital as well as in the community is particularly important; The National Cancer Patient Experience Survey Programme, undertaken by Quality Health on behalf of NHS England, highlights the progress that has been made with treatment of cancer, but also raises concern about a lack of progress on improving the patient experience, particularly for Londoners (Quality Health, 2013). The National Survey of Bereaved Relatives reported that relatives of people rated hospital Doctors and Nurses less well at ensuring that their loved ones were treated with dignity and respect, with hospice staff ranking highest (Office for National Statistics, 2014). Londoners who die in hospital following an emergency admission also have a longer length of stay than the National average. Recent events related to the withdrawal of the Liverpool Care Pathway have anecdotally had a negative impact on care. Specialist Palliative Care teams have responsibility for implementing new guidance about the care of dying people and this includes providing training for generalists much of which is already underway. All commissioned training should be evidence based, coordinated and evaluated, demonstrating impact and cost effectiveness.

Population projections suggest that the numbers and proportions of people from black, Asian and minority ethnic (BAME) groups will continue to increase and they will represent a larger proportion of older people. People from BAME groups are more likely to have unmet needs and/or disparities in palliative and end of life care (Calanzani N, 2013).

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The National Health Service has gone through turbulent times over the last 5 years, and hospital scandals have highlighted shocking reports of poor care in services such as Mid Staffordshire Hospitals NHS Trust and the Winterbourne Care Home. This has resulted in the public and government demanding more from its health and social care professionals, managers and commissioners, and holding them to account for care which falls below the expected standards of care in the 21st Century. The Francis Report (Francis R, 2013) highlighted the issues that can occur when a hospital places a greater focus upon finance than upon patient care, with too great a degree of tolerance of poor standards and of risk to patients, along with a failure to build up a positive culture, in nursing in particular, but also within the medical profession.

The report recommends that organisations should:

- Develop a set of fundamental standards, easily understood and accepted by patients, the public and healthcare staff, the breach of which should not be tolerated;
- Provide professionally endorsed and evidence-based means of compliance with these fundamental standards which can be understood and adopted by the staff who have to provide the service;
- Ensure openness, transparency and candour throughout the system about matters of concern;
- Ensure that the relentless focus of the healthcare regulator is on policing compliance with these standards;
- Make all those who provide care for patients – individuals and organisations – properly accountable for what they do;
- Ensure that the public are protected from those not fit to provide such a service;
- Provide for a proper degree of accountability for senior managers and leaders to place all with responsibility for protecting the interests of patients on a level playing field;
- Enhance the recruitment, education, training and support of all the key contributors to the provision of healthcare, but in particular those in nursing and leadership positions, to integrate the essential shared values of the common culture into everything they do;
- Develop and share ever improving means of measuring and understanding the performance of individual professionals, teams, units and provider organisations for the patients, the public, and all other stakeholders in the system;
- All health and social care support workers must undergo fundamentals in care training before being allowed to care for patients;

The nursing profession came in for heavy criticism and was aimed at directors, managers and clinical nurses and highlighted the poor education and training of health care assistants. For some, these recommendations require a major shift in attitudes to care delivery; education and training should give staff an opportunity to explore and embed these skills.

The Nursing and Midwifery Council has updated the Code of Conduct for nurses and midwives to highlight the importance of delivering fundamental care to dying people so that they can expect to receive the high standard of care afforded to any other person needing nursing care. In response to the report *More Care, Less Pathway* (Department of Health, 2013); the Nursing and Midwifery Council (NMC) has incorporated its fundamental care

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standards into its draft revised Code which is currently out for consultation (Nursing & Midwifery Council, 2014).

*“Anyone training to be a nurse in the UK is required to demonstrate that they can deliver care safely, competently and with compassion. Following the publication of More Care, Less Pathway in 2013 we published our standards for competence to make the public aware of the fundamental standards of care that a nurse is expected to be able to deliver. In addition, as part of the review of our Code, we have incorporated these standards into the draft to make sure that all nurses registered in the UK, regardless of where they trained, understand what the public expect from them.”* Jackie Smith, NMC Chief Executive and Registrar, 2014

The recent Cavendish Report (Cavendish, 2013) provided an independent review into healthcare assistants and support workers in the NHS and social care settings; healthcare assistants (HCAs) make up around a third of the caring workforce in hospitals, and research suggests they now spend more time than nurses at the bedside. It is cited that 60% of patient contact is delivered by non-registered staff. Healthcare assistants have no compulsory or consistent training and a profusion of job titles; this confuses patients, who often assume that everyone is a nurse, and it makes life difficult for some nurses, who are not always sure which tasks they can safely delegate. Some HCAs are now doing jobs that used to be the preserve of nurses, even doctors. The health care system should see healthcare assistants as a critical, strategic resource; yet many HCAs feel undervalued and overlooked.

The NHS has tended to treat HCAs and the registered nurses who supervise them as separate workforces. Health and social care staff should, through development and education, have the opportunity to enter new bridging programmes so that they may acquire the skills and qualifications to progress into professional training such as nursing, or one of the allied health care professions. There is overwhelming evidence that care outcomes improve when all staff feel valued as part of strong, self-reinforcing teams.

Cavendish goes on to say that the social care support workforce dwarfs that of the NHS. By helping people to live independently, frail and vulnerable people can be supported in their own homes and the strain on the NHS is reduced. Staff turnover rates of 19% a year in care homes and up to 30% a year in domiciliary care can negatively impact on the quality and continuity of care. For workers in this sector, “I’m only a carer” is too common a refrain. The phrase “basic care” dramatically understates the role fulfilled by this staff group. Helping an elderly person to eat and swallow safely, bathing someone with dignity and without hurting them, communicating with someone with early onset dementia; doing these things with intelligent kindness, dignity, care and respect requires skill as well as considerable maturity and resilience. Like healthcare assistants, social care support workers are increasingly taking on challenging roles, and having to look after more frail elderly people, yet their training is hugely variable. Some employers are not meeting their basic duty to ensure that staff are competent; the Cavendish report proposes minimum standards of competence before staff can work unsupervised, in the form of the “Certificate of Fundamental Care”.

The report also highlighted the challenge for managers and social care staff of navigating the sea of vocational qualifications and training courses which have developed in response to

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changing systems of government funding. Lack of faith in the system has led to costly duplication, as employers develop their own in-house courses, and retrain new staff irrespective of what training they have had elsewhere. The report calls for a rigorous quality assurance mechanism for training courses and vocational qualifications.

*“Despite the pressures, charities, hospices and other social care organisations are pioneering some of the most innovative approaches to person-centred care. The NHS has a great deal to learn from them about responding to individual needs, and values based recruitment.”* (Francis, 2013).

London is particularly challenged around recruitment and retention of health and social care professionals. High staff turnover and recruitment problems necessitate ongoing training opportunities for all staff.

The Chief Nurse uses the “6 Cs” to articulate the elements which apply to all delivering care regardless of professional background and job title (NHS, 2012). The 6 Cs are used as the foundation of good quality care and provide the pillars to support good end of life care.

The recommendations of the Francis and Cavendish Reports and the Chief Nurse’s 6 Cs, translate easily to all areas of care especially end of life care. The NHS core values (NHS, 2013) embed much of the recommendations of these reports cited above; end of life care education and training should aim to embed these values.



## **Recent guidance relating to end of life care**

Until the last decade, end of life care typically had a low profile within the NHS and was often been a low priority in terms of service improvement for both commissioners and providers.

In July 2008, the first ever National End of Life Care Strategy was published (Department of Health, 2008); it aimed to promote high quality care for adults at the end of life. The development of the end of life care workforce formed one of its chapters.

With regard to development of workforce, the key messages within the End of Life Care Strategy were:

- For a cultural shift in attitude and behaviour related to end of life care within the health and social care workforce. Death is inevitable and does not necessarily constitute a failure of care



- 
- For a focus on the resolution of the major deficiencies in the knowledge and skills of staff groups who come into frequent contact with people at the end of their lives, rather than on an expansion in the workforce
  - That programmes to enhance training for medical undergraduate/postgraduate and other pre-registration students will take longer to demonstrate benefits for people approaching the end of life, but are of equal importance in the long-term
  - Those staff delivering any aspect of end of life care have a personal responsibility to ensure they have the necessary skills and competencies to enable them to deliver high quality end of life care

Since the strategy was published, significant headway has been made, with a gradual increase in the number of people dying in their place of choice and an increased focus on advanced care planning; however recent reports suggest that there is still more to be done (Public Health England, 2013).

One of the tools championed in the strategy “The Gold Standards Framework” has been widely adopted, particularly in primary care and care homes and Electronic Palliative Care Coordination Systems (EPaCCS) such as *Coordinate My Care* are improving communication across care settings, particularly out of hours (Ipsos MORI Social Research Institute, 2011).

Following reports of concerns voiced by many patients’ families and some professionals, the Minister Norman Lamb set up an independent review of the Liverpool Care Pathway (LCP), another of the tools championed in the strategy. The review panel, chaired by Baroness Neuberger, published a report *More Care, Less Pathway* in July this 2013 (Department of Health, 2013). It recognized that people had peaceful and dignified deaths where the LCP was used properly, but that there were so many examples where it was not used well that it recommended phasing out the use of the LCP within 6-12 months.

The *National Care of the Dying Audit of Hospitals* (Royal College of Physicians, 2014) highlighted that the quality and provision of care for people dying in hospitals varies significantly. While every patient has different needs, and some will need more pain relief than others for example, there should be no variation in the quality and provision of services, or training in the care of people dying in hospitals. The audit shows that major improvements need to be made to ensure better care for dying people and better support for their families, carers, friends and those important to them. Hospitals have a responsibility to provide high quality care for people in their final days of life, and support for families, carers and those close to them. A small proportion of acute trusts across South London have access to face-to-face specialist palliative care services, 7 days per week (Murtagh F, 2012), despite a longstanding national recommendation that this be provided; most of the remainder provide face-to-face services on weekdays only or a six day service.

The RCP audit highlighted that nationally, mandatory end of life care training in acute hospitals was only required for doctors in 19% of trusts and for nurses in 28%.

82% of Trusts had provided some form of training in care of the dying in the previous year; 18% had not provided any.

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Based on its findings, the report makes 10 key recommendations aimed at driving up the quality of care for dying people across all trusts. The recommendations reflect key themes in the evidence base on care for dying people and those in the Neuberger Review. The recommendations are also in keeping with the work of the Leadership Alliance for the Care of Dying People, a partnership of organisations brought together to produce a system-wide response to address the issues raised by the Neuberger Review (Department of Health, 2014) (See below).

The report specifically recommended that “education and training in care of the dying should be mandatory for all staff caring for dying patients. This should include communication skills training and skills for supporting families and those close to dying patients”.

The National Coalition aimed at changing public attitudes to death, dying and bereavement “Dying Matters” report a reluctance of the public and professionals to talk about dying and plan ahead - despite this, 80% of the public believe all adults should be required to have a will to avoid disputes after they have died and 90% of the public agree that all healthcare professionals should receive compulsory training in how to talk sensitively to people who are dying and their families (Public Health England, 2013).

In June 2014, the report produced by the Leadership Alliance for the Care of Dying People published their response to *More Care, Less Pathway*, the report, *One Chance to Get It Right* (Department of Health, 2014) outlines the following priorities of care:

When it is thought that a person may die within the next few days or hours:

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

## **Strategic Aims & Vision**

This strategy aims to ensure that the health and social care workforce in South London have the skills and confidence to deliver holistic, compassionate care for the dying and their families regardless of where they are cared for. Implementation of the strategy will help ensure incremental improvements and spread of high quality end of life care to all those who need it, regardless of pathophysiology, place of care or other characteristics which may have an impact on access to care.

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Specifically, the strategy aims to:

- Promote the development of a well trained workforce, leading to improvements in the overall quality of EoLC, including increases in patient choice, the quality of communication with patients & carers, and increased levels of patient & carer satisfaction, by improved communication between care givers
- Contribute to the development of a culture within the health & social care workforce in which death will not be regarded as a failure and a good (expected) death is seen as a successful care outcome
- Ensure a full range of education and training opportunities relating to end of life care are available across South London, to enable the health and social workforce to be confident and competent in delivering care to dying people and their families
- Ensure training and education is offered to all groups of staff including non-registered staff, volunteers, and those who predominantly deliver social care
- Provide opportunities for staff to develop their careers with clear opportunities for progression into more technical/skilled and/or senior roles
- Increase the choices available and improve the experience of care for dying people and their relatives by having a more competent workforce across all care settings
- Improve staff morale due to increased confidence in knowledge and skills in end of life care reflected in staff survey and reduced attrition
- Enable those responsible for end of life education and training commissioning to procure appropriate training from suitable education providers in a systematic and strategic manner
- Ensure that those involved in the delivery of end of life care education and training have the skills, knowledge and capacity to meet the challenges set out above
- Develop consistent standards for education training delivery across South London and to share learning more widely
- Develop networks and relationships with and between specialist palliative care providers who provide ongoing guidance & support for health and social care staff delivering end of life care
- Support the development of competencies and/or recognise existing competencies which have been evaluated and have currency and transferability across health and social care settings, avoiding duplication of training.

## **Outcomes**

In order to support the delivery of this strategy, the following outcomes should be locally measured and demonstrated:

- The number of health and social care staff (by staff group, care setting and Clinical Commissioning Group) who have the appropriate knowledge and skills to provide high quality end of life care when caring for dying people and their families has increased
- The availability and consistency of palliative and end of life care training has increased for all disciplines

- 
- End of life care training is embedded in training curricula at all levels and for all staff groups
  - End of life care training is delivered & assessed by staff who are competent in palliative/end of life care
  - A change in practice demonstrated through patient satisfaction surveys and audits
  - Staff morale is improved due to increased confidence in knowledge and skills in end of life care reflected in staff surveys and reduced attrition/turnover

## **Commissioning education provision**

On 1 April 2013, there was a major reorganisation of the National Health Service and the changes set out in the Health and Social Care Act (2012) came into force. New clinical commissioning groups (CCGs) took responsibility for allocating resources to secure high quality services, with the freedom to commission services from any service provider which meets NHS standards and costs; these could be NHS providers, social enterprises, voluntary organisations or private sector providers. CCGs are supported by NHS England who allocate resources and commission certain services such as primary care.

The establishment of Health Education England (HEE) and Local Education and Training Boards (LETBs) from 1 April 2013 was intended to ensure that education, training, and workforce development could drive the highest quality public health and patient outcomes, and achieve good value for money. HEE were given the responsibility to provide national leadership and oversight on strategic planning and development of the health and public health workforce and to allocate education and training resources.

It is critical that education commissioning is led by the care needs of the population and is locally managed to meet the needs of employers. Under this new system there is more emphasis on local knowledge and employers have a greater say in developing their workforce. The Local Education and Training Board (Health Education South London, or HESL) is supporting healthcare providers and clinicians across South London to take greater responsibility for planning and commissioning education and training.

The national strategy identifies one of the most pressing tasks as defining the core principles and competencies required by each staff group when they deliver care. As illustrated in the following diagram, agreeing and establishing competencies for care is vital to ensuring that the correct training is available to develop a skilled and knowledgeable workforce; the workforce also need to understand and appreciate their limitations and understand where further support and help can be accessed when caring for dying people and their families.

Commissioners and providers of education and training should encourage Skills for Care and Skills for Health to develop competencies which have currency/ recognition and transferability across health and social care settings and for those individuals who acquire them to have transferability across health and social care settings. Where new programmes

are developed locally, these should be shared with national agencies to avoid duplication and drive improvement elsewhere.

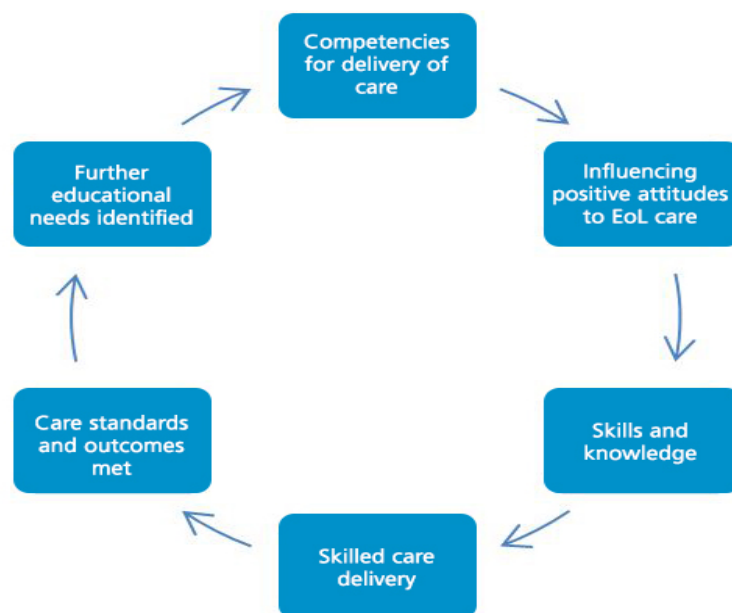


Figure 2

To support health and social care organisations to ensure staff have the right competencies, skills, attitudes and demonstrate compassion; Specialist Palliative Care and/or Education Providers should be appropriately commissioned<sup>6</sup> to ensure they have the necessary capacity to deliver education and training and to provide ongoing support to all those health and social care staff who are involved in the delivery of end of life care.

This will not be a quick fix and will require successive years of investment to educate, train and support existing and new staff. Education and training programmes must be locally or regionally commissioned, developed and delivered to ensure the workforce are confident to deliver competent, compassionate end of life care.

Releasing care professionals from practice across all settings to teach on accredited education is a major resource issue, as their priority is often to deliver clinical care. Specialist palliative care providers, dedicated end of life care staff (e.g. Macmillan GP leads) need to be appropriately commissioned to deliver education, training and support programmes in order to ensure health and social care staff, are confident, competent and have the right attitudes to deliver compassionate care. This will ensure the recommendations outlined in the Francis and Cavendish Reports are implemented in a coherent and cost effective manner.

<sup>6</sup> Services may be commissioned locally and/or regionally by individual provider organisations, CEPNs, CCGs, HESL etc.

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All commissioned care providers are expected to invest in education and training to ensure they have a competent workforce in necessary areas of clinical practice; this is funded through a variety of means including their own investment in mandatory training, and investment in direct and indirect Continuous Professional and Personal Development (CPPD) from Health Education South London. In addition, HESL have invested in the commissioning and delivery of education based on local needs through the new Community Education Provider Networks (CEPNs) and Strategic Networks. The membership of CEPNs can include, although is not limited to, GP surgeries, community pharmacies, community dentists, community optometry, community service providers, acute providers, voluntary sector and higher education institutions. Some of the key benefits of CEPNs can include:

- multi-professional education;
- streamlining educational governance and commissioning arrangements;
- real-time primary and community workforce data;
- enhanced clinical and educational outcomes through the use of peer review.

Most importantly, where CEPNs have been established, education and training can be more closely tailored to the needs of local communities and more easily aligned to service priorities.

One of the greatest challenges to developing the local healthcare workforce is the need to ensure appropriate provision for groups that have traditionally received less training once they have qualified. Community nurses, community pharmacists and emergent practitioner groups (such as care navigators and health champions) are among these groups. CEPNs offer an opportunity to support the development of these groups while seeking to expand capacity and capability for more established professional groups.

Workforce planning and education commissioning is not currently integrated between health and social care service planning and strategic commissioning intentions, and as many people at the end of life will also be relatively “high” users of social care, it is important that this is explored. Education investment is not always adequately aligned to service need and future development and educational outcomes are often of variable quality and fail to meet the needs of employers; this strategy seeks to set some standards around quality of education and training delivery.

Health Education South London has outlined a number of priorities for the education they commission (see Appendix 3), and end of life care education and training should be designed with these priorities clearly in view.

The South London Palliative Care Oversight Group will provide HESL with expert advice to support decision-making in regard to allocation of funding for training for specialist palliative and end of life care across all sectors and care settings.

Education & training programmes should only be commissioned where the quality and effectiveness of the programme has already been demonstrated, or in the case of new programmes; an evaluation and dissemination of this is planned. A number of such

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programmes exist already and HESL have invested in the delivery of these as well as in the development of some new models of education and training (see Appendix 4). It is desirable that all commissioned training and support programmes be accredited/ kite marked as being effective and fit for purpose.

Specific guidance on commissioning end of life care education is to be found in *One Chance to Get It Right* (Department of Health, 2014), see appendix 5 & 6 for further details.

## Care Providers

South London has an extremely diverse range of providers involved in the care of people at the end of life. These range from tertiary centres, district general hospitals, urgent care centres and community hospitals to community and homecare providers, primary care, hospices and care homes. There is also a vast range of voluntary sector providers providing advice, support and advocacy generally or for specific groups. Local Authorities provide a significant amount of domiciliary care directly and indirectly through private and not for profit agencies and increasingly, citizens are choosing to “purchase” their own care directly from organisations and individuals.

Appendix 7 gives an overview of the range of organisations involved in providing care across S London.

## Workforce

As well as there being a broad range of providers of care/ employers; there is an incredibly wide range of staff roles involved in the delivery of care for dying people. The workforce includes: doctors, nurses, physiotherapists, occupational therapists, dieticians, speech and language therapists, social workers, care managers, chaplaincy teams, pharmacists, psychological support staff, ambulance staff/ paramedics, complementary therapists, health and social care assistants and ancillary staff such as ward clerks, GP receptionists and clinical administrators, commissioned hospital transport staff and care workers.

Of these, the specialist palliative care workforce is relatively small; approx. 5,500 nationally when compared to the total number of health and social care professionals and non-registered staff who deliver end of life care, which is estimated to be 1.3 million across health care (Health Education England, 2014).

Specialist staff working in palliative and end of life care have a clear role in teaching, supporting and modelling good practice, however in order to meet the challenge of training the large number of staff who comprise the ‘non-specialist’ end of life care workforce, education and training should be appropriately purchased through a variety of core and ad hoc education commissioning.

In recent years, a model of ‘high facilitation’ has been used in care homes, nationally and in South London, to support improvements in the skills and confidence of care home staff. When sustained over longer periods of time, this has succeeded in supporting more people

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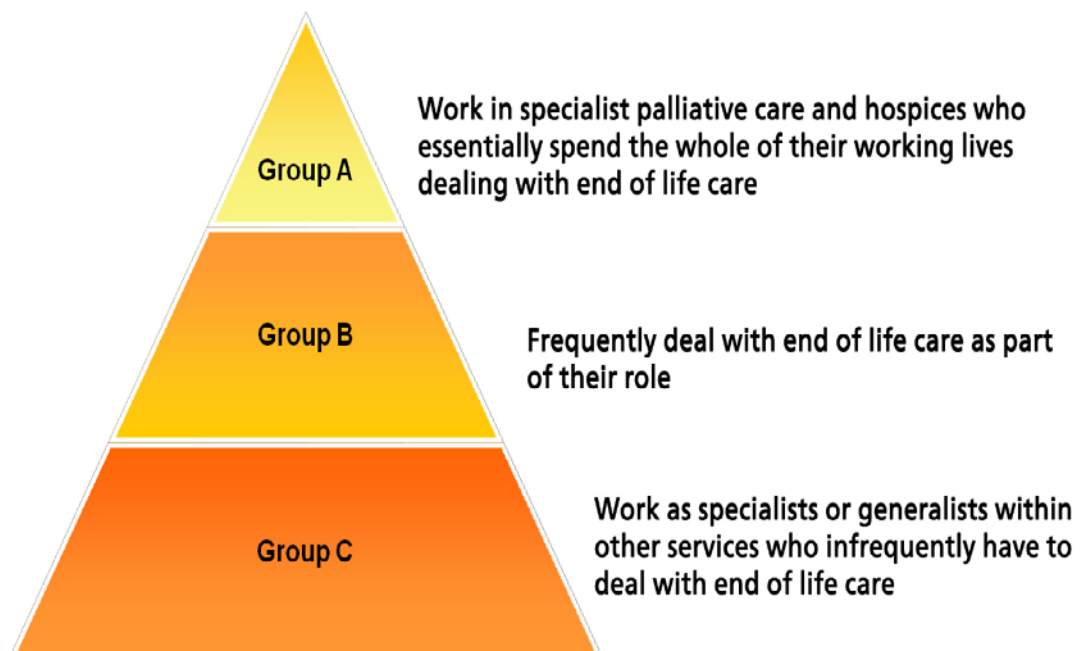
to remain in their care home, with improvements in the quality of care and reduced hospital admissions. The relatively 'weak' context of care homes requires such an approach (Hockley J, 2006) and it is reasonable to draw comparisons between the context in care homes and that of other sectors such as domiciliary care and some hospital wards.

The solution proposed within the national end of life care strategy is to segment this workforce into three groups, as illustrated below.

This strategy outlines the suggested minimum levels of skills and knowledge for Groups B and C. In order to achieve the aims of this strategy; the group with the greatest training needs is those who come into contact with dying people regularly, although it is not a core part of their role and often who have received little if any training in this area.

With regard Group A, specialist training and education is provided through universities, hospices and other specialist providers; the Mental Health and Psychological Support Pathway Group of the London Cancer Alliance is currently reviewing the training available regarding "Advanced Communication Skills" which remains a requirement for Cancer Peer Review, and the needs of the Specialist Palliative care workforce will be reviewed as part of this.

Figure 3: End of Life Care Workforce Groupings





Group A:	Group B:	Group C:
<p>Staff working in specialist palliative care and hospices who essentially spend the whole of their working lives dealing with end of life care. This includes: Physicians in palliative medicine, palliative care nurse specialists &amp; allied health professionals, hospice pharmacists, senior palliative care pharmacists, chaplaincy teams, social workers</p> <p>&amp; all health &amp; social care staff working in specialist palliative teams or hospices</p>	<p>Staff who frequently deal with end of life care as part of their role. This includes: Secondary care staff working in A&amp;E, acute medicine, respiratory medicine, and care of the elderly, cardiology, oncology, renal medicine, long term neurological conditions, intensive care, hospital chaplaincy teams &amp; social workers and some surgical specialities.</p> <p>Primary care staff including GPs, district nurses, practice nurses, community matrons, some care home staff, ambulance staff and community based carers</p>	<p>Staff working as specialists or generalists within other services who infrequently have to deal with end of life care. This includes: Other professionals working in secondary care or in the community, for example, care home staff and extra care housing staff, day centre and social care staff not involved in hospices, as well as domiciliary care and prison services staff</p>

## Underpinning principles for end of life care education and training

This education and training strategy seeks to ensure that the principles of good general care are reflected throughout; however it is important to be explicit about the following principles when developing and delivering training:

- An active, holistic and compassionate approach to care that ensures respect for and dignity of the patient and family including their spiritual needs
- Partnership in care between the patient, family, health and social care professionals
- Regular and systematic assessment of patient/ carer/ family needs incorporating patient consent at all times
- Advance care planning/ risk stratification in accordance with patient preferences
- Patient choice about place of care and death
- Anticipation and management of deterioration in the patient's state of health and well-being
- Recognition of the process of dying

- 
- Understanding of the bereavement process and bereavement care expertise
  - Sensitivity to personal, cultural and spiritual beliefs and practices
  - Effective coordination of care across all teams and providers of care (in statutory, voluntary and independent sectors) who are involved in the care of patient and family

To ensure providers and commissioners have the appropriate workforce across health and social care; that all staff are confident and competent to deliver holistic, compassionate end of life care for their patients; and to meet the needs of their carers and family, there is a need to identify and address gaps in workforce capacity.

## **Training needs analysis**

When undertaking a training needs analysis, commissioners, CEPNs and providers of end of life care education and training should consider that such education and training is not delivered in isolation - it is core to long term conditions such as stroke, dementia, Motor Neurone Disease, Chronic Obstructive Pulmonary Disease, Heart Failure and Cancer. Training needs analysis should address the five priority areas – communication skills, assessment and care planning, Advance Care Planning, symptom management and family support/bereavement for all levels of staff who frequently deal with end of life care as part of their role.

Each provider of care should consider how they will release staff for training and education and where employed/contracted, how their Specialist Palliative Care staff will be supported to have the capacity to fulfil their responsibilities to implement this strategy. Board member leads for end of life care are responsible and accountable for working with all stakeholders within their organisations to ensure that end of life care is improved, and that staff are adequately trained.

### **Suggested questions regarding End of Life Care for inclusion in training needs analysis:**

- Would you be confident that your workforce could communicate competently with patients and carers to support them with Advance Care Planning?
- Would you be confident that your workforce can assess and plan care to minimise pain and other symptoms for people with life limiting illness?
- Would you be confident that your workforce has the skills to offer high quality bereavement support?

## **Programme design and delivery**

Once training needs have been identified, commissioners and providers should work together to determine the current level of education and training provision in order to inform a gap analysis across the sector/local area:

- 
- Identify gaps in end of life care education provision and begin by addressing priority areas
  - Explore existing good practice or design, pilot and evaluate appropriate education packages to meet the needs of all staff across all care sectors, including care homes, acute, primary and voluntary sector service providers
  - Promote the development of “core” training packages and implement innovative methods of delivery
  - Provide training in communication skills (at a level appropriate to the practitioner) for all staff across all sectors
  - Ensure that content of courses encompasses all aspects of the end of life care pathway and staff are equipped and enabled to support their own needs and those of team members when delivery of care is challenging

In many cases this can be delivered through higher education providers, CEPNs or Strategic Networks delivering training commissioned by HESL.

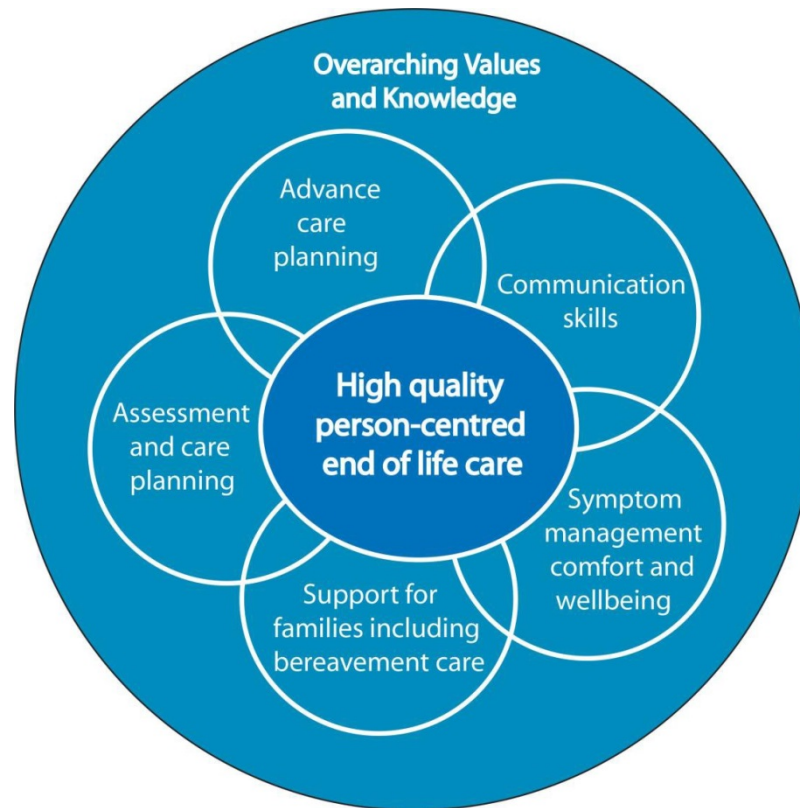
## **Education programme priority areas**

In order to achieve the aims of this strategy; the group with the greatest training needs are those who come into contact with dying people regularly, although it is not a core part of their role, often they will have received little if any training in this area. The focus should therefore be on Group B (page 18) initially, and then on Group C.

To ensure the workforce work using a multi-professional team approach and are confident and competent to deliver compassionate care; education, training and support should broadly be developed and delivered around the following five themes of high quality person-centred end of life care.

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## Core competencies for end of life care<sup>7</sup>



1. **Communication Skills:** Staff need to be confident and competent to discuss ethical concerns and decisions made when the patient lacks capacity. Staff understand the importance of communicating with and supporting family members and friends as well as the dying person. Where appropriate, registered professionals are competent in discussing issues related to DNACPR, artificial hydration and nutrition etc.
2. **Advance Care Planning/Risk Stratification:** Staff are comfortable talking about issues related to prognosis, preferences for care and place of care, the use of advance decisions to refuse treatment/lasting power of attorney. Staff understand the importance of discussing issues with carers in relation to do not attempt resuscitation and refusal of treatment. Staff understand the mechanisms for documenting and sharing these discussions with the wider health and social care team (e.g. use of Coordinate My Care).
3. **Assessment and Care Delivery and Planning:** Staff are able to recognise, assess and understand the changing care needs of the dying person in their individual social and cultural context. They are confident and competent in assessment of need and

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<sup>7</sup> Adapted from "Developing end of life care practice: A guide to workforce development to support social care and health workers to apply the common core principles and competences for end of life care" (Skills for Care, 2012)

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prioritising care. Staff have an understanding of the services and professionals available and are able to participate in multi-professional discussions. Staff understand the need to gain consent for all aspects of care and assess mental capacity and take this into account as part of their assessment. Staff are able to provide information and support for family members following death and through bereavement.

4. **Symptom Management: Comfort & Wellbeing:** Staff are competent in assessing symptoms and providing advice and treatment for relief of symptoms including the use of syringe pumps and other equipment (where appropriate). Staff are aware of specialist services who can support them and the patient with advice around controlling symptoms and more complex interventions for social, psychological, spiritual and cultural needs.
5. **Support for Families including Bereavement Care:** Staff understand the importance of supporting families, friends and informal caregivers of the person who is dying and are skilled at managing care in the immediate after death period and throughout bereavement.

For each area of training, competencies should be developed based around four groupings of staff to ensure delivery of education, training and support at the appropriate level according to the necessary skill set of each workforce group.

1. Volunteers
2. Health and Social Care Assistants/ Non Registered Workforce
3. Registered/Professional Health/ Social Care Workforce
4. Medical Staff

Where possible multi-professional education and training should be provided as this is how care is delivered, and it gives staff an opportunity to gain a better understanding and appreciation of each other's roles and responsibilities, plus a recognition of each person's unique contribution in the patient pathway.

As highlighted in the Cavendish report (Cavendish C, 2013), there should be a greater consideration of the robustness of the assessment of learning and competence for all levels of staff and where individuals fail to meet these standards, they should be supported to develop or removed from practice.

A number of new developments and existing programmes are underway to address the end of life care training needs of the workforce. A selection of these are listed on page 23-30.

## Education providers

A wide range of providers deliver end of life care education in south London, including Universities, Colleges, NHS Palliative Care Teams and Hospice providers. Historically, Hospices have been somewhat under-utilised as education providers with little strategic planning around capacity for commissioning of education.

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All acute hospitals, community providers and Hospices are engaged in pre-registration education to a certain degree and most are involved in providing practice placements for post graduate medical training; however the capacity of the sector to provide specific palliative care programmes has not been assessed as a whole. Recent inclusion of Hospices into the allocation of CPPD funding is a positive step, and data relating to the use of this will help to inform HESL about workforce, skills and capacity in the future. Greenwich and Bexley Community Hospice is currently participating in the project to agree the quality of practice placement standards across south London.

In the past, care homes and private hospitals have had to privately commission small packages of bespoke education, and other education has been provided free with the aim of supporting more people to remain in their place of choice and prevent attendance at Emergency Departments and/ or Hospital admission. The needs of this sector should continue to be assessed as part of the big picture. Some care homes are now positioning themselves to become “teaching care homes” and centres of excellence; the benefits of this approach should also be evaluated.

## **Examples of existing programmes and new developments**

There are a number of well-established end of life care training programmes available in south London, as well as some recent developments. Those featured below are examples of the range of courses available, and the list is not exhaustive.

### **Generic courses**

#### **Gold Standards Framework for Care Homes**

The GSFCH© training programme is a widely used and well-evidenced quality improvement programme with an accreditation process for quality assurance. GSF is a nationally recognised marker of excellence endorsed by the Department of Health and Care Quality Commission.

The programme aims to improve the quality and experience of care for care home residents and their carers, improve coordination and collaboration for integrated cross boundary care and improve cost effectiveness, decreasing hospitalisation, enabling more people to die where they choose.

GSFCH is provided by St Christopher’s Hospice and care homes undergoing training are supported by all adult Hospices in south London.

#### **QELCA©**

The QELCA© programme integrates a work-based learning experience with facilitated classroom reflection and the model is designed to be delivered by specialist clinicians who

have undertaken the QELCA “train the trainers” programme.

The programme, originally designed to be delivered by hospice nurses to senior nurses working in acute hospitals is now being provided by a number of south London Hospices to multi-professional senior staff working in the full range of care settings. The course is provided over five days, using the hospice setting as a learning resource, participants are offered a first-hand experience of observing and being alongside specialists as they deliver expert care to dying people and their families. In addition to the practice experience, learners will participate in classroom discussion and reflection facilitated by experienced palliative care professionals. The programme then continues with six months of facilitated action learning sets so that action plans for self, team and organisation can be supported in practice and learning can be consolidated.

QELCA© (Quality End of Life Care for All) was designed by St Christopher’s Hospice and evaluated, in partnership with the NHS National End of Life Care Programme and Help the Hospices and seeks to role model end of life care to participants, equipping and empowering them to deliver better care to patients on their return to practice. There is evidence that the course motivates participants to introduce care for self and their teams into their organisations and to lead change in culture.

## **Development of Assistant Practitioners in End of Life Care**

Working with Skills for Health and Skills for Care, a set of common core requirements for End of Life care linked to occupational standards have been developed to support the new role of “Assistant Practitioner”. This role and the associated training package are being developed to help improve the care of people approaching the end of life. In a project led by South London Hospices, the role will be piloted across south London with support and funding from Health Education South London.

## **Review and development of nationally accredited vocational qualifications**

Traditionally end of life care has been viewed as a specialist area of work; in reality it incorporates all elements of the daily lives of people nearing the end of their lives. A quality experience of social care is now seen as pivotal to those individuals at the end of their lives.

Skills for Care have produced a number of resources to support those working in adult social care to develop their skills and knowledge in this area. The National End of Life Care Programme, in partnership with Skills for Care and Skills for Health have developed guidance on “Developing End of Life Practice, a guide to workforce development to support social care and health workers apply the common principles and competencies for End of Life Care (Skills for Care, 2012). The challenge of training and assessing such a large part of the workforce is large, improved care and experience for people approaching the end of life will only be improved if this part of the workforce’s contribution is valued and their development fully supported.

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Working with the South London Hospices Education Collaborative, St Christopher's Hospice is leading on the development of a Certificate of Fundamental Care for Health and Social Care Support Workers. A model for working with a local Further Education provider is being developed.

## **Transforming End of Life Care**

The course is taught by a variety of members of the specialist palliative care team and the hospital chaplain. The course is being formally evaluated by academic colleagues in order to inform future developments.

This two day course, developed by Guy's and St Thomas's NHS Foundation Trust, provides multi-professional education for all staff working in acute and primary care. The course covers specific aspects of end of life care (the last days of life, managing uncertainty, symptom management, prescribing, family and bereavement, culture and spirituality, discharge processes, communication skills and ethics and the law) and aims to improve self-perceived confidence and competence in these areas. Course content is based on National and local policy and guidance and integrates knowledge of organisational and community clinical practice covered by the service.

## **Developing volunteers to support people with long term conditions or who are at the end of life and their carers**

Hospices have a long history of involving volunteers to supplement the paid workforce in a wide variety of roles. In south London, hospices are increasingly utilising trained volunteers to support the paid workforce to deliver care and support. Roles range from advocacy and befriending roles to more practical support and "hands on" care.

A project has been established by the South London Hospice Education Collaborative to further explore the roles that volunteers can fulfil and to develop a standardised, accredited training programme for patient-facing volunteers in order to add value to services for people at the end of life.

Training will be adaptable to ensure that "specialist" training can be incorporated for specific roles. Once developed, this training will be available to other health and social care providers to enable them to take forward their own volunteer projects.

## **Training for Coordinate My Care**

Coordinate My Care (CMC) is a clinical service that coordinates care and aims to facilitate people to achieve their choices and improve their quality of life. The CMC service is introduced to a patient by a clinician who has a clear understanding of the person's medical, nursing and social history to create a record of their personalised care plan. The person is asked to provide consent to have the details of their care plan entered onto the CMC IT system and subsequently shared with care providers who have a legitimate reason to



access this information.

Throughout the last three years, CMC has acted as an enabler to embed End of Life Care across London and training projects related to its roll out have been many and varied.

For 2014/ 15 it is planned to further embed CMC in other EoLC education initiatives to build upon those elements that have been successful in previous years, coordinate training providers to meet local need and avoid duplication.

An example of a previously successful approach is Richmond CCG, who commissioned the Difficult Conversations training to GPs across the borough. This was highly respected training which rather than be seen as a standalone module, was seen as a building block for EoLC competency with CMC acting as an enabler to record and share information.

Going forward, training will be broken down into modules supported by uniform training packages, delivered by palliative care experts, so that HESL can confidently commission training that delivers improved outcomes for dying people and their families.

It is proposed that CMC training is divided into three stages:

1. Awareness
2. Using CMC (including how to create/update a record with a patient)
3. Support once you're using CMC – may be provided 1-1 or in small teams

And that where possible, training for stages 1 & 2 are incorporated into other programmes.

## **The European Certificate in Essential Palliative Care (ECEPC)**

This is an eight week distance learning course delivered by eight Hospices across the UK, Eire and Malta and coordinated centrally by Princess Alice Hospice, Esher.

Since its inception in 2000, the course has been successfully completed by over 2,000 doctors, nurses and allied health professionals seeking greater knowledge of the holistic care of people at the end of their lives.

The course material is delivered in the form of a course handbook and supported by a Virtual Learning Environment. Candidates are assigned a facilitator to support them in the production of a reflective portfolio and undertake a written exam and viva.

## **Communication skills**

### **Sage and Thyme**

The SAGE & THYME ® model was developed by clinical staff at the University Hospital of South Manchester NHS Foundation Trust (UHSM) and a patient in 2006. It was designed to train all grades of staff how to listen and respond to patients/clients or carers who are distressed or concerned. It places published research evidence about effective

communication skills within a memorable structure for clinical practice.

‘SAGE & THYME’ is a mnemonic which guides healthcare professional/ care workers into and out of a conversation with someone who is distressed or concerned. It provides structure to psychological support by encouraging the health worker to hold back with advice and prompting the concerned person to consider their own solutions.

SAGE & THYME is designed for foundation level communication, suitable for any member of staff (e.g. medical secretary, outpatient clerk, nurse, physiotherapist, doctor, social worker, student) and for any specialty. It is suitable to be used with patients and carers, students, colleagues and children – anyone who is distressed or concerned – inside and outside of health and social care.

A number of organisations in South London are accredited to deliver SAGE & THYME training.

## **Connected – National Advanced Communications Skills**

The importance of good communication in cancer care has been highlighted in successive reports, and this course was established by the National Cancer action team to enhance senior healthcare professionals’ abilities to deal with challenging communication situations.

The course, which is facilitated by nationally accredited trainers, includes discussion of the research evidence surrounding communication in cancer care, interactive exercises and role-play in small groups with actors. Participants practise skills and receive positive and constructive feedback in a safe and supportive environment.

The agenda for the course is set by the participants in response to their personally identified learning needs. Participants are expected to take part in all aspects of the course.

A number of organisations in South London have accredited facilitators for Advanced Communications Skills training.

## **Difficult Conversations©**

Difficult Conversations© is a standardised, highly interactive workshop that uses simulation and discussion to draw on the experiences of the participants. It’s a unique appraisable course developed to empower health and social care professionals to facilitate ‘difficult conversations’ with patients/service users around end of life care, cancer and long term conditions. Developed in partnership with RCGP, RCN, British Geriatric Society, Dying Matters and Macmillan Cancer Support, it links with specialist palliative care providers in each locality to signpost to local experts in palliative care.

In addition, there is a *train the trainer* programme available, where key individuals can be identified from within the community to train and be certified in Difficult Conversations© as an official facilitator. This is targeted at experienced trainers.

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## Miscellaneous

### Schwartz Center Rounds®

Schwartz Center Rounds are a practical tool that health and care providers can use to improve the culture of their organisation and support staff.

The Point of Care Foundation is the sole licensed provider of training and support to organisations wishing to run Schwartz Center Rounds in the UK.

Rounds are in use in a number of organisations across the UK including some Hospices and can be helpful to improve multi-professional communication across THE WHOLE care team.

More information is available on [www.pointofcarefoundation.org.uk](http://www.pointofcarefoundation.org.uk)

## Shaping the Strategy

The London Cancer Alliance held an end of life care education stakeholder event in June 2014 where the End of Life Care Education and Training Strategy was shared with stakeholders for comments and feedback. At the event, there was general support for the strategy, with further suggestions to reflect the overarching approach to the care of dying people and their families, embedding holism, compassion and dignity as central to care delivery. Training should stress the importance of cultural sensitivity; a patient and family focus and also include something on assertiveness so the workforce is confident to escalate any problems, concerns or gaps in skills/ knowledge.

In addition, participants felt that, where possible, education should be delivered in a multi professional manner to reduce the tendency for silo working, integrated between health and social care (being aware of the differences in language used) and including support of people who are bereaved as well as “self-care”. Attention to the emotional burden of caring for dying people and how to increase resilience was felt to be very important to include as part of any course or intervention which focuses on end of life care. QELCA® provides an example of how this aspect can be incorporated in training courses.

Training should reflect the pathway approach to care, including recognition of the process of dying. Education and training should be “blended” and include observation, role modelling and reflection.

All Health and Social Care staff regardless of their status and grade should be viewed as an integral part of the “MDT” with a valid and valued contribution to the care of dying people. The strategy should consider how it will impact/ support difficult to reach staff i.e. those working in home care where access to education and training may be limited.

As already identified in the general principles, it was felt that education and training programmes should be accredited/ kite marked so those involved in the direct care of people, managers and commissioners are confident that the products are fit for purpose and provide value for money. It was suggested that an education and training “passport” should

be developed to enable staff to move from one setting to another and not have to repeat similar modules where they are deemed competent. An approach such as this is currently being explored for Foundation Year Doctors working in south London.

## Mandatory End of Life Care Training

As part of the discussion, the suggestion of mandatory end of life care training was raised in several groups. As the Care Quality Commission increases its focus on the quality of end of life and palliative care within organisations, this is likely to be something that organisations consider implementing.

## Public Education around Death, Dying and Bereavement

The importance of educating the public about death and dying was raised as part of the discussions at the stakeholder event, While this is an important issue, this strategy does not seek to address this; the National Coalition Dying Matters provide further guidance on raising public awareness of death and dying. [www.dyingmatters.org.uk](http://www.dyingmatters.org.uk)

## Priority groups

As resources are limited and the strategy will take time to fully implement, stakeholders were asked at the event in June to vote on who they felt were the priority staff groups to be targeted for training:

GPs	28
Hospital Doctors – all grades	18
Care Home Staff	18
Hospital Registered Nurses	14
Hospital Health Care Assistants	12
Community Nurses	11
Home Care /Housing Staff	11
Social Workers	10
Other community professionals (health)	8 (not named)
Hospital Ancillary Staff, Porters, A&C, Housekeepers etc.	6
Practice Staff	1
Allied Health Professionals including Chaplaincy	1

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## Implementation

The success of this strategy will be judged on its implementation which should be locally driven by Commissioners, Community Education Provider Networks, Care Providers and Education Providers.

Significant investment has been made by Health Education South London to support the delivery of training for health care staff in end of life care, but without the commitment of employing care organisations who will also use their CPPD resources, support the release of staff and support culture change, education and development will not have the significant impact that is needed.

By carrying out thorough training needs analysis, targeting high priority groups and working with specialist palliative care, end of life care and education providers to develop/ commission training to meet learners needs, not only will organisations be able to develop their workforce to be more confident and competent in end of life care; there will also be improved communication between specialist and generalist providers and improvements in the care pathway for people facing the end of their lives.

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## References

- Bardsley M, Georghiou T, Dixon J, 2012. *Social care and hospital use at the end of life*: Nuffield Trust.
- Bryan L, Manns J, Thavaraj A et al, 2013. *Quality End of Life Care for All (QELCA ©): A national pilot of a nursing workforce development initiative – Evaluation Report*, London: St Christopher's, Help the Hospices, NHS Improving Quality.
- Calanzani N, Koffman J, Higginson IJ, 2013. *Palliative and end of life care for black, Asian and minority ethnic groups in the UK*, London: Marie Curie Cancer Care.
- Cavendish C, 2013. *The Cavendish Review- an independent review into Healthcare assistants and support workers in the NHS and social care settings*, [www.gov.uk](http://www.gov.uk)
- Department of Health, 2008. *End of Life Care Strategy: promoting high quality care for adults at the end of life*, London: Department of Health.
- Department of Health, 2013. *More Care, Less Pathway- Review of Liverpool Care Pathway for Dying Patients*, London: Department of Health.
- Department of Health, 2014. *One Chance to Get it Right*, London: Department of Health.
- Francis R, 2013. *The final report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*, [www.midstaffpublicinquiry.com/report](http://www.midstaffpublicinquiry.com/report) (Accessed 3rd January 2014).
- Gomes B, Cananzani N, Curiale V et al, 2013. *Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers*. The Cochrane Library, Volume DOI: 10.1002/14651858.CD007760.pub2, published online.
- Health Education England, 2014. *The talent for care: consultation on a national strategy to develop staff working in NHS roles banded 1-4*, Health Education England.
- Hockley J, 2006. *Developing high quality end of life care in nursing homes: an action research study*, Edinburgh: Unpublished PhD thesis. University of Edinburgh.
- Ipsos MORI Social Research Institute, 2011. *End of Life Locality Registers Evaluation*, s.l.: Social Research Institute.
- Murtagh F, McGinn M, Sykes N, 2012. *LCA mapping of Specialist Palliative Care Services*, London: unpublished.
- National Council for Palliative Care, 2012. *National Survey of Patient Activity Data for Specialist Palliative Care Services*, London: Public Health England.
- NHS, 2012. *Our culture of compassionate care*: NHS.
- NHS, 2013. *The NHS Constitution*: NHS.

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Nursing & Midwifery Council, 2014. *The Code: Standards of conduct, performance and ethics for nurses and midwives*. draft revised version ed. Nursing & Midwifery Council.

Office for National Statistics, 2014. *National Survey of Bereaved People (VOICES) by NHS Area Team (England) 2011-12*, s.l.: Office for National Statistics.

Royal College of Physicians, 2014. *The National Care of the Dying Audit for Hospitals*, London: Royal College of Physicians (RCP) in collaboration with the Marie Curie Palliative Care.

Public Health England, 2013. *What we know now 2013: New information collated by the National End of Life Care Intelligence Network*, London: Public Health England.

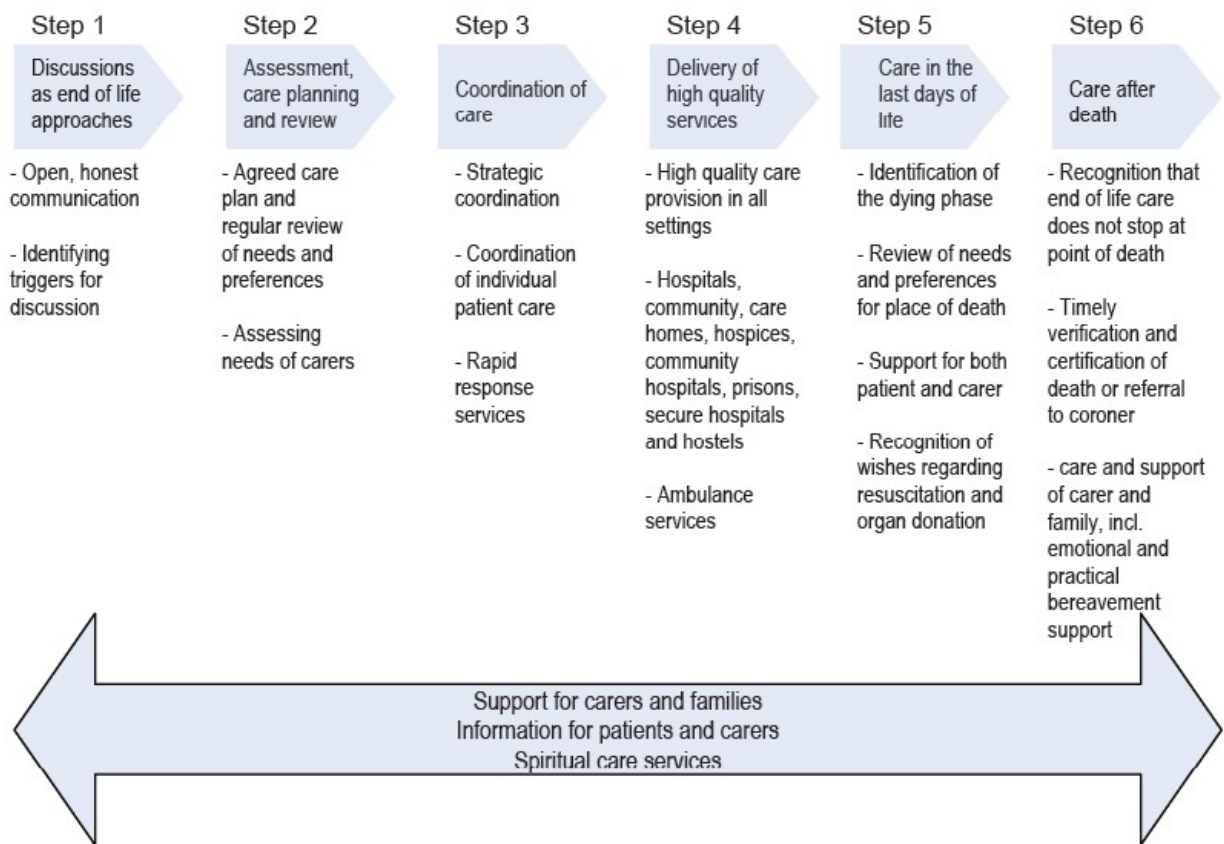
Quality Health, 2013. *National Cancer Experience Survey*, <http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>: online.

SE London Palliative & End of Life Care Network, 2008. *SE London Palliative & EOLC Education Strategy*, London: Unpublished.

Skills for Care, 2012. *Developing end of life care practice: A guide to workforce development to support social care and health workers to apply the common core principles and competences for end of life care*": Skills for Care/Skills for Health/National End of Life Care Programme.

# Appendix 1: End of Life Care Pathway

## The End of Life Care Pathway



(Department of Health, 2008)



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## **Appendix 2: Findings from Phase 1 of the Marie Curie Delivering Choice Programme in South East London (2008)**

The Phase I investigation for the Delivering Choice Programme highlighted various issues and barriers to the education and development for professionals, which were categorized under the following headings:

- Recognition of palliative care patients and the dying phase/Identification of their needs
- Communication Skills/Breaking Bad News
- Patients with LTC needing palliative care
- Palliative Care Knowledge and Skills
- Utilising appropriate specialist resources i.e. Palliative Care Team
- Preferred Priorities of Care (PPC)
- Care Homes
- Attendance and access to Education and Training sessions/events
- Support/Advice/Information for families and carers
- Continuing Health Care Funding

Further detail on each of these issues is available from the full report.

It also outlined the findings and topics for further training for two professional groups that are critical in delivering care in the community (GPs and DN's).

### **General Practitioners (GPs)**

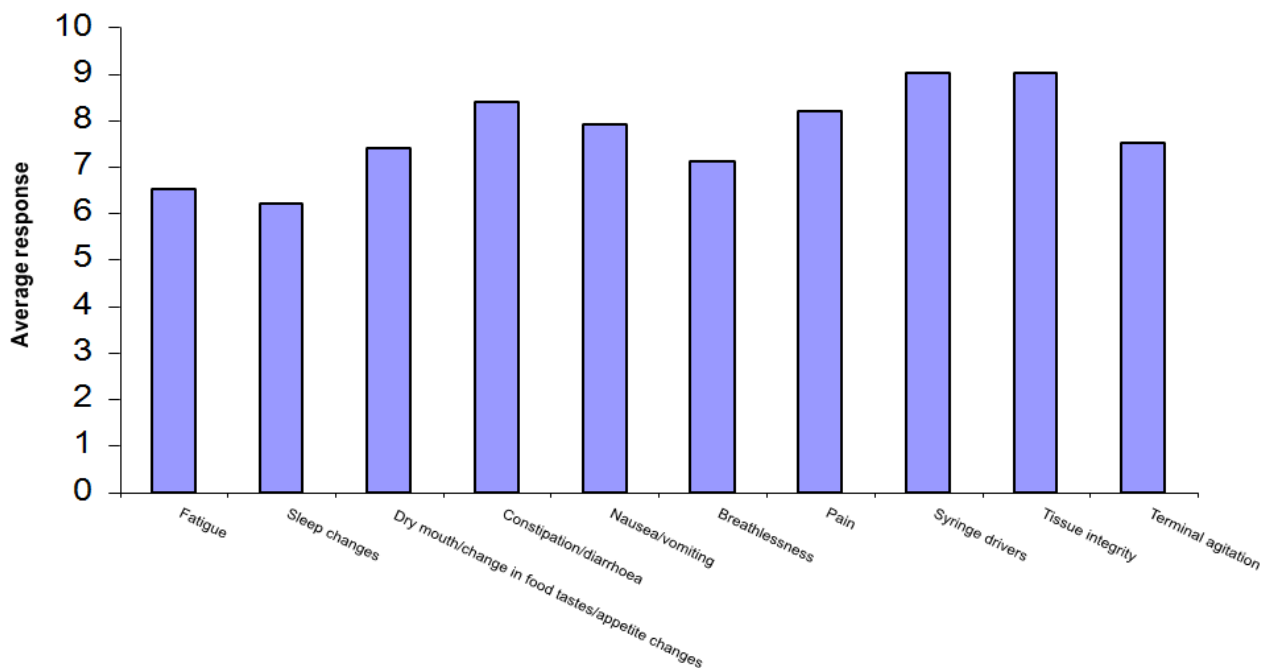
106 GPs responded to questions related to their training needs in palliative care including specific topics that they would like refreshing or further training on. Answering the question if they would like further training in palliative care, 84% of the respondents answered that they would benefit from further training in palliative care. The topics that were highlighted for further training include:

- Breaking bad news
- Addressing end of life issues with patients and family
- Dealing with psychological issues
- Addressing social needs
- Spiritual care
- Cultural aspects in palliative care and issues related to ethnic groups
- Dealing with palliative care emergencies
- Symptom management: Pain management; dealing with patients symptoms other than pain: nausea; itching

- Medicines management: - new approaches and update on current drug management; Update on syringe drivers
- Review of current clinical care and modern advances; Keeping abreast of developments
- Advanced directives
- Advice on Benefits
- Update on communication
- How to help young children in bereavement situation

## District nurses (DNs)

41 DN's responded to the questionnaire. The respondents scored themselves of their ability in managing a list of physical symptoms [score: zero (not effective) to ten (very effective)]. The respondents scored around average for managing physical symptoms such as fatigue;



sleep changes; and breathlessness.

Further questions in understanding their training needs in addressing psychological, social and spiritual issues showed that approximately half of them would have benefited from further training on dealing with psychological, social and spiritual issues.

Effectiveness in addressing patient and family concerns regarding psychological issues	29% felt they were average in this area	44% felt they would benefit from training in this area
Effectiveness in addressing patient and family concerns	29% felt they were average in this area	54% felt they would benefit from training in this area

regarding social/relationship conflict issues		
Effectiveness in addressing patient and family concerns regarding spiritual issues	37% felt they were average in this area	56% felt they would benefit from training in this area

63% of the respondents answered that they will benefit from training on cultural aspects in palliative care and issues related to ethnic groups.

The following were highlighted as areas where additional training would be beneficial:

- Symptom control and updates on managing nausea, fatigue, vomiting, breathlessness, pain, constipation; spinal cord compression, titration of analgesia; agitation; bladder retention; Sleep disturbance; Dry mouth/appetite; problems with profuse bleeding; anxiety/agitation
- Blood result interpretation
- Update on new medications and drug available
- Psychological support
- Counselling; Dealing with family carers not accepting diagnosis; how to deal with relatives; answering difficult questions; how to advice patients;
- Managing: All types of cancer including symptom control after Chemotherapy; heart disease; end stage heart failure; Lymphodoema; MND, HIV, CCF; COPD; Parkinson's, MS, Renal failure
- Respiratory training

## Care Homes

A survey was also undertaken with care home managers about palliative care training within care homes. 31 care home managers responded to the survey. 97% of the respondents felt that their staff would benefit from further training in palliative care.

	Yes	No
Have any staff in the care home received training in palliative care and end of life care?	18 (58%)	13 (42%)
Do you feel that staff would benefit from more training in palliative care?	30 (97%)	1 (3%)

The following were highlighted as areas where additional training would be beneficial:

- Symptom control, keeping a person comfortable & pain free; recognising changes in patient;
- Use of syringe driver for pain control

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- Physical disabilities i.e. M.S, muscular dystrophy, stroke and diabetes
  - End of life for frail elderly people and mental health.
  - Cancer, Parkinson, Dementia, CCF and COPD, renal failure; Alzheimer's disease and Dementia; liver disease
  - How to deal with depression, Parkinson's disease and confusion
  - Basic physiology for metastatic disease
  - Communicate bad news and communication with relatives; listening skills, working with families; counselling and bereavement
  - How to approach relatives and patients regarding the advanced directive
  - Ethics surrounding "not for resuscitation" instructions
  - How staff could implement GSF and how to explain GSF to family

## Appendix 3: Health Education South London Priorities

To achieve a workforce that:	Our focus will be:
<ul style="list-style-type: none"> <li>• Works effectively as a key enabler of system change, engaging with local communities and providers of services</li> <li>• Has the ability to manage change and ensure the quality of training is maintained</li> <li>• Retains and supports its good people during major change programmes, using their skills to empower patients to inform that change</li> <li>• Shows continuous improvement based on contribution to and the application of the most up-to-date clinical evidence, and feels empowered to innovate at all levels and professions</li> <li>• Enables social mobility, increasing participation from those who might not otherwise consider further education, and is representative of the community it serves</li> <li>• Demonstrates the highest potential to develop and deploy the skills, attributes and behaviours patients need</li> <li>• Represents value for money by translating investment in education and training into productive careers representative of the direction of health and social care</li> <li>• Always has the patient's interest at heart by acting in line with the NHS Constitution's values</li> <li>• Works in an integrated and supportive environment that values individual and collective contributions</li> <li>• Has the skills, attributes, values and behaviours to promote wellbeing and to provide high quality care needed by patients</li> <li>• Is trained and educated to reflect the way it increasingly operates: in multi-</li> </ul>	<ul style="list-style-type: none"> <li>• Maintaining and enhancing multi-professional leadership</li> <li>• Developing productive relationships between staff, students and patients</li> <li>• Developing workforce planning systems to reflect the demand on all providers of care</li> <li>• Enhancing the quality of supervision and learning for all our learners, and supporting the development of all staff providing NHS funded services in South London</li> <li>• Ensuring workforce development programmes enable staff to work effectively within different settings and across organisational boundaries</li> <li>• Ensuring effective collaboration with our Academic Health Science Network to design and spread innovation</li> <li>• Attracting and developing a diverse workforce that reflects the diversity of our population</li> <li>• Promoting best practice in recruitment to programmes across our network of members</li> <li>• Targeting the use of CPPD funding to support the workforce's career planning and development and Lifelong Learning</li> <li>• Embedding the NHS's values in staff from the point of recruitment and throughout their working lives</li> <li>• Developing clinical and educational trainers and supervisors to ensure high quality learning environments for all staff and learners</li> <li>• Supporting HEIs and employers to embed the NHS Constitution's values across their organisation</li> <li>• Developing community based education</li> </ul>

<p>disciplinary, inter-professional teams and in community-based roles encompassing prevention of ill-health, and promotion of re-ablement, recovery and rehabilitation</p> <ul style="list-style-type: none"> <li>• Is trained and educated through quality-assured outcomes-based learning methods that fit with the way our students, trainees and staff learn best</li> <li>• Has clear and visible, values-driven leadership at all levels and in all professions</li> <li>• Recognises the importance of, and is equipped to enable, patient education and empowerment</li> </ul>	<p>provider networks</p> <ul style="list-style-type: none"> <li>• Fostering placements that provide opportunities for all learners in community and hospital learning environments</li> <li>• Integrating quality assurance processes across all areas</li> <li>• Prioritising leadership development across all domains</li> <li>• Creating environments in which opportunities for inter-professional learning are maximized</li> <li>• Embedding principles of patient empowerment in all programmes of learning</li> </ul>
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## Appendix 4: EoLC Training Commissioned by Health Education South London

Provider	Staff Group	Programme
Greenwich & Bexley Community Hospice <a href="http://www.communityhospice.org.uk">www.communityhospice.org.uk</a>	Registered Nurses – Band 6+ Older age settings (hospital, community, care homes)	Improving EoLC for Older People
Southwark CEPN	All groups of health and social care professionals, including healthcare assistants and care home staff,	To develop a CEPN around multi-professional community workforce development in palliative and end-of-life care.
King's Health Partners	multi-disciplinary sessions	Transforming End of Life Care
Princess Alice Hospice	to pre qualified H&S care professionals	Sage & Thyme
St Christopher's Hospice <a href="http://www.stchristophers.org.uk">www.stchristophers.org.uk</a>	Healthcare Assistants and Social Care Support Workers	Development of QCF level 3 diploma in LTC and EoLC
S London Hospices Collaborative	Volunteers	Developing a training package for patient facing volunteers working in end of life care and dementia
S London Hospices Collaborative	Assistant Practitioners (band 4)	Development and implementation of assistant practitioner role
S London Hospices Collaborative	Band 6 and above Multi Professional	Quality End of Life Care for All (QELCA)
St Raphael's Hospice	Home care and care home staff	Quality Improvement in End of Life Care: Bringing the 6 Cs to the End of Life Care of people in Nursing Homes, Residential Homes and their own homes
Lewisham & Greenwich NHS Trust	Multi-disciplinary hospital staff	Improvement in end of life care provision in the acute setting

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## Other Commissioned Education

Provider	Staff Group	Programme
Greenwich & Bexley Community Hospice	Care Home Staff	Gold standards framework (care homes) High Facilitation and intensive support
St Christopher's Hospice	Care Home Staff	Gold standards framework (care homes) High Facilitation and intensive support

## Appendix 5: Recommendations for Education, Training and Professional Development

*(Taken from One chance to get it right pages 31-33)*

1. The issues raised by the review panel's report require substantial action on education, training and professional development. It is clear from the report that some staff caring for dying people do not have the skills and knowledge required to deliver care to high standards; and in some cases, they are not putting into practice the values that underpin such care.
2. Particular members of the Alliance have specific responsibilities for ensuring that initial training<sup>8</sup> for particular groups of staff equips them to carry out their roles effectively. This document describes action Alliance members have taken and will take to ensure this happens. Individual providers of health and care are responsible for ensuring their staff have the experience and competence they need to do their jobs well. This includes making time and other resources available for staff to undergo professional development. Staff themselves have responsibilities to ensure that they have the necessary skills to do their jobs and to keep those skills up-to-date. This document also describes action Alliance members have taken and will take to support service providers and individual health and care staff to deliver their responsibilities in relation to education and training on caring for dying people.

### Training for Doctors

1. Many of the competencies that are needed to deliver effective care for people in the last few days and hours of life are generic: i.e. they are also relevant to caring for other people. The Shape of Training Review, which reported to the GMC on 29 October 2013, stressed that future postgraduate curricula would need to encompass the generic

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<sup>8</sup> including post-graduate training required for qualification.



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professional capabilities that all doctors should possess (or be able to develop) to ensure the delivery of good quality care across all specialties. The GMC is working with the Academy of Medical Royal Colleges to identify what these are. They will include some fundamental areas of practice such as the need to communicate effectively, empathise, lead, follow and be diligent and conscientious as well as those more related to end of life care, such as partnership and team working.

2. Further support for doctors' ongoing professional development is available through a document being produced by the Specialty Advisory Committee for Palliative Medicine of the Royal College of Physicians, the Joint Royal Colleges Postgraduate Training Board and the Association for Palliative Medicine of Great Britain and Ireland. This outlines how physicians training in a range of medical specialties can gain the required competences in palliative care. (Panel recommendation 10 refers to training for doctors.)

### Ongoing education and training for all health and care staff

3. Alliance members are clear that all staff who have contact with dying people must have the skills to do this effectively and compassionately. This includes clinical and support staff (e.g. porters, reception staff and ward clerks.) Those organisations that deliver such care have the prime responsibility for ensuring that the people they employ are competent to carry out their roles effectively, including facilitating and funding ongoing professional development, where this is appropriate. The Alliance's Implementation Guidance for Service Providers and Commissioners includes advice to help those organisations ensure they are carrying out their responsibilities to ensure staff have the necessary training and skills in this area. This advice includes desired characteristics of programmes of education and training for staff that care for people in the last days and hours of life. The desired characteristics include taking an educational approach which employs evaluation methods that can demonstrate achievement of outcomes and, ideally, extend beyond the immediate end of the training course or event. The Alliance is creating a mechanism for sharing practice, and enabling evidence of its effectiveness, to be shared. The Alliance intends that those who fund, commission or provide training for health and care staff should use the 'desired characteristics' it has developed and its mechanism for sharing good practice, to help them develop specifications for specific training, education, professional development and learning packages that include care in the last few days and hours of life.

On content, the Alliance's advice includes that such education and training cover:

- Specific attention to the topics of nutrition and hydration: assessment, discussion and shared decision-making with the person (where possible), and those important to them and other health and care team members.
- Symptom management: assessment, communication and shared decision-making wherever possible about use of medication (including route of delivery), physical measures (including repositioning) and safe and accurate prescribing.
- Communication skills, including empathy and recognising emotional response to stress and distress, discussing uncertainty, conversations about limits of treatment including 'Do

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not attempt cardiopulmonary resuscitation' (DNACPR), withholding and withdrawing treatment, preferred place of care and death, etc.

(Panel recommendations 11, 16, 19 and 22 refer.)

4. Alliance members consider there is scope for those arranging training for health and care staff who care for dying people and their families to make greater use of Health Education England's e-Learning for Health e-learning programme on end of life care (e-ELCA). e-ELCA<sup>9</sup> is a library of over 150 highly interactive sessions of e-learning on end of life care, which aims to provide a resource for enhancing the training and education of health and care staff involved in delivering end of life care to people. The sessions are arranged in four core modules (advance care planning; assessment; communications skills; and symptom management, comfort and wellbeing), with three additional modules (social care, bereavement and spirituality) and one 'integrating learning' module which helps to consolidate and apply understanding in different situations.
5. Despite its high regard, soundings taken by the Alliance suggest that the use of e-ELCA to support education and training remains patchy in some parts of England. The Alliance notes that the breadth of e-ELCA can make it difficult for busy practitioners to make choices and that its potential to be used as part of a blended approach to learning is not fully realised. Hence, it will seek to provide guidance on factors that maximise the effectiveness of e-ELCA. GMC will consider the possibility of including information about e-ELCA in its wider work to enable doctors to identify and access learning opportunities on end of life care; and its work to promote its guidance on *Treatment and care towards the end of life: good practice in decision-making*, 2010<sup>10</sup>
6. Individual Alliance members are keen to run joint education and training days throughout England to support care in the last few hours and days of life. For example, the RCGP, Marie Curie, Macmillan and the GMC are exploring the possibility of a collaboration to deliver one-day educational workshops on excellent personalised care and symptom control in 2014. The RCP is also considering plans to produce a toolkit on care for people in the last few days and hours of life to identify current problems and suggest ways of improving quality.
7. Training for the assessment and meeting of spiritual needs of dying people, their relatives and carers in any setting can be accessed from chaplaincy departments. Training can support the use of a variety of approaches, including FICA (the acronym FICA refers to: F - Faith and Belief, I - Importance, C - Community and A - Address in Care). Further details of this are at Annex I.

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<sup>9</sup> Further information on end of Life care for all (e-eLca) is available at: [www.e-lfh.org.uk/projects/end-of-life-care](http://www.e-lfh.org.uk/projects/end-of-life-care)

<sup>10</sup> Available at: [www.gmc-uk.org/end\\_of\\_life.pdf\\_32486688.pdf](http://www.gmc-uk.org/end_of_life.pdf_32486688.pdf)

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## Assessment and evaluation of training, education and learning to support health and care staff caring for dying people.

8. The Alliance has produced Implementation Guidance for Service Providers and Commissioners. This states that education and training programmes for care in the last hours of life should take an educational approach which includes how to apply learning to practice and evaluation methods that can demonstrate achievement of outcomes and will, ideally, extend beyond the immediate end of the training course or event. (Panel recommendation 22 refers.)
9. Health Education England will work with stakeholders to influence training curricula as appropriate, although the content and standard of clinical training is ultimately the responsibility of the professional bodies. Education and training of the existing workforce is primarily an employer responsibility. (Panel recommendation 35 refers.)

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## **Appendix 6: Recommendations on desired characteristics of education and training programmes for care in the last days of life**

***For use by those who commission, fund or procure such programmes for health and care staff involved in care of the dying person. One chance to get it right, pages 103 – 104, DH 2014***

As a minimum, such education and training programmes should include:

### **Learning Objectives**

These are high level objectives as they need to be adapted to suit the programme, its duration and format, and its intended learners. Depending upon role they should focus from awareness to application to complex assessment and decision-making. They should include:

By the end of the training programme, learners are able to:

- Describe how to assess and act upon the needs of a dying person: physical, psychological, emotional, social, spiritual, cultural & religious.
- Explain how to address the dying person's comfort, specifically in relation to food, fluids and symptoms.
- Discuss how to approach and implement individualised care planning including shared decision-making.
- Demonstrate how to communicate about dying with the person, and those who are important to them.
- Describe how to assess and act upon the needs of the dying person's family and those important to the person.
- Describe the importance of and act upon maintaining own and team resilience through reflective practice and clinical supervision.
- Demonstrate understanding of how Mental Capacity Act should be applied when the dying person lacks capacity.
- Demonstrate understanding of the impact of loss and grief, including how to support individuals who are bereaved.

Additionally, for clinicians:

- Describe how to recognise that dying may be imminent, assess reversibility, make appropriate decisions and plans for review, and communicate uncertainty

### **Content**

- Assessing the person whose condition has changed, including how to gather information from that person and those important to them, and other health and care team members, make professional judgements about the potential reversibility of the condition (and if so, whether or not reversing the condition is the right thing to do) and take appropriate action, including seeking senior advice or second opinion if necessary.

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## Assessing and discussing the physical, psychological, emotional and social needs of the dying person.

- Assessing and discussing the spiritual and/or religious needs of dying patients, and those important to them.
- Specific attention to the topics of nutrition and hydration: assessment, discussion and shared decision-making with the person (where possible), and those important to them and other health and care team members
- Symptom management: assessment, communication and shared decision-making wherever possible about use of medication (including route of delivery), physical measures (including repositioning) and safe and accurate prescribing.
- Assessing and addressing the needs of those important to the dying person, including in bereavement.
- Communication skills, including empathy and recognising emotional response to stress and distress, discussing uncertainty, conversations about limits of treatment including 'Do not attempt cardiopulmonary resuscitation' (DNACPR), withholding and withdrawing treatment, preferred place of care and death, etc.
- Clarity in verbal and written handovers between professionals, and across shifts/duty periods and settings (e.g. community and hospital care) to ensure consistent care and communication with the person and those important to them.
- An appreciation that caring for people in the last days of life is not just about 'doing' or 'fixing' things. It is concerned with supporting the person and those that are important to them during the dying period.

## Educational approaches

- Employer commitment to ensure the delivery of appropriate end of life education programmes to health and care workers.
- Employee commitment to attend and implement learning from end of life education programmes.
- Explicit learning outcomes which include how to apply learning to practice, and supports implementation of advice from the Leadership Alliance for the Care of Dying People.
- Teaching methods which include some element of experiential learning, and encourages reflective practice as part of continuing professional development, and life-long learning
- Evaluation methods which can demonstrate achievement of outcomes and ideally extend beyond the immediate end of the course/training event.

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## Appendix 7 – South London Health and Social Care Landscape



## Key Facts:

- **12** Health and Wellbeing Boards
- **12** Clinical Commissioning Groups
- **12** Local authorities
- **12** Healthwatch organisations
- **7** Higher Education Institutes and Universities including two medical schools
- **31** education and training placement providers
- Estimated **60,000** plus NHS workforce
- **504** surgeries across South London
- **9** Acute Trusts
- **2** Mental Health Trusts
- **9** Community Healthcare providers
- **7** Hospices
- **Hundreds** of other voluntary and community sector organisations

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## **Appendix 8: South London End of Life Care Education and Training Strategy; Stakeholder Feedback from the 18th June 2014 London Cancer Alliance Event**

Comments on the Strategy and the 3 priorities from each of the 4 groups:

- There should be an education and training passport in relation to the 4 cornerstones
- Education should be delivered in a multi professional manner to prevent, minimise silo working, should be integrated and reflect the pathway approach to care
- All Health and Social Care staff regardless of their status and grade should be viewed as an integral part of the “MDT” with a valid and valued contribution to the patient/persons care.
- Patient Centred Care must include the family & Carers
- The 4 Cornerstones language needs to change to reflect overarching themes – holism, compassion, dignity
- Cornerstones need to include recognition of process of dying, care of the dying patient and include bereavement or another cornerstone
- The strategy must consider how it will impact/support difficult to reach staff i.e. those in social care setting where access to education and training
- All staff must be mandated to have end of life care skills or mandate certain groups
- Staff should include how it will support staff in relation to the emotional burden of caring
- Education and training for the public around the 4 cornerstones, dying matters approach
- Education and training should be blended but not e-learning
- There should be a passport of education and training undertaken so allows transfer of prior learning across care settings
- Education and training programmes, courses should be accredited/kite marked so those involved in the direct care of people, managers and commissioners are confident the products are fit for purpose and value for money
- Communication should be culturally sensitive; family focused and also include something on assertiveness so the workforce is confident to escalate to a more senior person of the “MDT” for advice and support i.e. SCA has the confidence to ring a GP for advice
- Raised that some staff have limited communication skills (including ancillary staff and support workers) the recruitment process should include an assessment of communication, which should be at a certain level in terms of verbal and written skills.
- Language differences between health and social care- care planning means differing things to different people! E.g. Advance Care Planning